



Whole Family Pathway

The importance of the whole-family approach

Young carers do not care in isolation from the rest of their family. Although they need support for themselves, their needs should also be considered in the context of their whole family.

A resource for practitioners

It is important to ensure that, whoever or however the family (Parent or Child) in need of support first makes contact with an agency, the same processes or pathway is followed, and that at all times the outcomes of *Every Child Matters* are considered.

This is not an assessment tool but a 'map' for both families and agencies to follow so they can see what choices, what responsibilities and what lines of accountability for services may be available.



ENTER

The Children's Society is a leading children's charity committed to making childhood better for all children in the UK. Our national network of centres and projects deliver specialist services for children who face disadvantage in their daily lives. Our schools work, children's centres and mentoring programmes help children develop the skills and confidence they need to make the most of their childhood and play a full part in their local communities. Our research and campaigning aims to influence the thinking of everyone - including politicians and decision makers - creating real change and making childhood better for all children.

Key among our areas of operation is the work we do to support children and young people who care for parents or siblings who suffer from chronic illness or disability; children who are denied a childhood by the obligations they feel to care for others. Many of these children are bullied and face social exclusion and poverty. We protect children's rights, 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.

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Think Family: Improving the Life Chances of Families at Risk (2008) sets out a vision for a local system that improves the life chances of families at risk and helps to break the cycle of disadvantage. It outlines the key characteristics of a system that thinks family at all levels, from governance to the frontline.

“Where young people take on caring roles, work to ensure they receive adequate support and services that safeguard their childhood and aspirations as children and young people.”

“Social workers need to understand that all families are different and that it is important to consider ALL the family members and their needs, not just ‘one member’. Please also understand that family and individual circumstances change – the person cared for may not know how they will feel from day to day, or week to week and this affects the level of support we need. Services need to be flexible.”

(Young carer)

LINKS



Think Family: Improving the Life Chances of Families at Risk



Family Pathfinders



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How to use the Whole Family Pathway

- This resource is not designed as a book to be read from cover to cover. Instead it is an electronic tool for ALL practitioners to use and access the information and 'sections' of the Pathway most useful to them in their role.
- When supporting families where there is ill health and disability remember to signpost this Pathway to colleagues from other departments (including Adults and Children's Services, Health, Education and the Voluntary Sector) providing support to the same families so they can access the sections in the Pathway relevant to the service they provide.
- Use the links on each page to navigate your way through the information in the Pathway or you can return to the contents page at any point to enter a new section.
- When using the Whole Family Pathway, refer to the Key Principles of Practice for supporting young carers and their families.

If you find a broken link within the Pathway please let us know: include-project@childrenssociety.org.uk

LINK



Why use the Whole Family Pathway?



Key Principles of Practice for working with young carers




Are you working with a young carer or a family where there is an illness, disability or alcohol or substance misuse?

What makes these children and their families different is that they may have needs which need to be addressed jointly by children's agencies and adults services in the widest sense and by all agencies involved in community care.








Introduction: why use the Whole Family Pathway?

The **Children's Plan** launched in 2007 by the Department for Children, Schools and Families sets out plans for the next ten years under each of DCSF's strategic objectives. The Children's Plan states that, for young carers, services should adopt a whole family approach.

This means that children's and adult services **MUST** have arrangements in place to ensure that no young person's life is unnecessarily restricted because they are providing significant care to an adult with an identifiable community care need.

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Introduction: why use the Whole Family Pathway?

This is a tool for all adult and children's services, education, health and other agencies who have contact with young carers and their families.

Funded by the DCSF, The Children's Society Young Carers' Initiative has developed this Whole Family Pathway, to ensure that however a family (Parent or Child) in need of support first makes contact with an agency, the same key points are followed.

The pathway has been piloted in three Local Authorities but has been written as a tool for all Local Authorities in England.

continued 

“Everyone involved should talk to each other and work together. They need to recognise that we know what’s going on because we live it every day. They need to listen to us and our parents.”

(Young carer)

LINKS

Local authority partners' websites



Hampshire



Hillingdon



Oxfordshire



Disabled Parents Network



Princess Royal Trust for Carers

The Whole Family Pathway has been developed in partnership with the Disabled Parents Network and the Princess Royal Trust for Carers.

Disabled Parents NETWORK



Introduction: why use the Whole Family Pathway?

It is advocated that:

- children’s and adults’ services develop joint whole family assessment processes that focus on:
 - a) How the assessment can support the person who needs care, including any parenting support needs.
 - b) Recognising the needs of any young carer.
 - c) Recognising the needs of the whole family.
 - d) *Every Child Matters*.
- the development of cross agency whole family assessments should provide an opportunity








for service providers to be proactive rather than reactive and should provide effective partnership working interdepartmentally, across agencies to help to close the gap between children’s and adult’s services.

- every Local Authority should have a Young Carers Strategy, and a Disabled Parents Strategy that includes Protocols for joint assessment and support between Adults’ services and Children’s services. Children’s Trusts should have a procedure for working with Adults’ Services. (What has your Local Authority got in place?)

The pilot work identified that it will be important to ensure that Common Assessment Framework (CAF) and Single Assessment Processes enable mechanisms for Children’s and Adults’ services to work together. In particular how the CAF can be used by adult services as a tool to identify if a children may need support for themselves.

This pathway highlights the roles and responsibilities of agencies who may need to offer recognition and support to these families.

LINKS

-  Definition: ‘person who needs care’
-  Definition: ‘young carer’
-  Hampshire Young Carers Strategy: a good practice example
-  Joint assessment and support protocols
-  What is a Children’s Trust?
-  Common Assessment Framework
-  Single Assessment Process

Young carers and their families can be found in all communities, and these young people often find themselves excluded from personal and social opportunities, including education, which inhibits their own development and future potential.

Definitions

Defining a young carer

Several definitions of a 'young carer' exist in legislation and guidance.

The original definition:





- "A child or young person (under age 18) who is carrying out significant caring tasks and assuming a level of responsibility for another person, which would usually be taken by an adult." (Social Services Inspectorate, 1995)




Other definitions include:

- "Children and young people (under 18) who provide or intend to provide a substantial

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-  12 Why do children and young people take on caring responsibilities?
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Defining a young carer *continued*

amount of care on a regular basis.” (The Carers (Recognition and Services) Act 1995)

- “Anyone under the age of 18 whose life is in some way restricted because of the need to take responsibility for the care of someone who is ill, has a disability, is experiencing mental distress, or is affected by substance misuse.” (Carers National Association (now Carers UK) 1998)
- “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.” (Becker, S. (2000) ‘Young Carers’, in Davies, M. (ed.) *The Blackwell Encyclopaedia of Social Work*. Oxford: Blackwell Publishers Ltd, p. 378.)

LINKS

-  What do you do if you identify a young carer?
-  Young carers in hard to reach communities
-  Carers (Equal Opportunities) Act 2004: Practice Guidance

Problems arise when the level of responsibility taken on by the young person is inappropriate to their age and maturity.

“Being a young carer can have detrimental effects on young people, including problems at school, health problems, emotional difficulties, isolation, lack of time for leisure, feeling different, pressure from keeping family problems a secret, problems with transition to adulthood, lack of recognition and feeling they are not being listened to.”

The Practice Guidance to the Carers (Equal Opportunities) Act 2004 (Social Care Institute for Excellence, 2005)

Defining a disabled parent

The Pathway has adopted a broad and inclusive definition of 'disabled' to include anybody with actual or perceived physical, sensory, emotional or learning impairment, long-term illness, HIV, drug or alcohol dependence or a person with a mental health issue. It recognises that not all parents included in this definition would define themselves as disabled people. Parents include prospective parents, biological parents,

grandparents, same sex couples, those who raise, adopt or foster children and step-parents.

Some disabled adults, with parenting responsibilities, will have both 'personal care' needs and also support needs with respect to their parenting roles or responsibilities. Other disabled adults may not have personal care needs, but may still require support or assistance to fulfil their parenting roles and responsibilities which will prevent their children from having to undertake inappropriate responsibilities. Many disabled adults with parenting responsibilities will not have any 'specialist' needs other than to access the same choices and opportunities for them and their children as other non-disabled parents.

People who provide social and health care services should not assume that family members will be able and willing to take on or continue caring for a disabled person. No one should be obliged to give up paid work or educational opportunities because of a lack of services to a disabled member of their family.

Someone who is seeking help from services should be given every assistance and opportunity to express their own point of view. Advocacy, support and translation should be made available if needed.

LINKS



Disabled adults with parenting responsibilities



Advocacy



Nature of illness and disability



Translation services



Points to consider on referral



Why do children take on caring responsibilities?



Who do young carers care for?

Those cared for may include:

- siblings
- biological parents
- grandparents
- same sex couples
- those who raise, adopt or foster children
- step-parents.

In some incidences children may care for friends or other members of the community, particularly unaccompanied children.

This care may be given to any one of these individuals with:

- physical disability
- sensory disability
- emotional or learning impairment
- long-term illness
- blood-borne viruses (including HIV/AIDS)
- drug or alcohol dependence
- mental health issues
- victims of war and torture.

The cared-for person may not necessarily live as a member of the young carer's household.

It should also not be assumed that all children whose parents are ill or disabled are automatically young carers.

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Statistics

- The 2001 Census figures state that in England there are approximately 139,000 children under 18 years providing unpaid care within their family (see table, right). However, this is still an underestimate, as it does not include those caring for parents who have an alcohol or drug dependency.

The question asked was: *“Do you look after, or give any help or support to family members, friends, neighbours or others because of:*

- *long-term physical or mental ill-health or disability, or*
- *problems related to old age?”*

- The Home Office estimates 250,000 young people live with parental substance misuse (*Hidden Harm*, Advisory Council on Misuse of Drugs, June 2003, Home Office)
- 920,000 children live in homes where one or both parents have an alcohol problem (National Association for Children of Alcoholics Preliminary Survey Findings, Bristol 2000).

Hours of unpaid care provided by children and young people

Age	Hours of care provided			Totals
	1-19	20-49	50+	
0 to 4	-	-	-	0
5 to 7	3,872	484	727	5,083
8 to 9	5,933	566	805	7,304
10 to 11	12,766	1,098	1,240	15,104
12 to 14	37,173	3,178	2,760	4,3111
15	16,941	1,700	1,188	19,829
16 to 17	40,138	5,258	3,372	48,768
Totals	116,823	12,284	10,092	139,199

Source: Census 2001 (Office of National Statistics)

- For more information and statistics see *Young Carers in the UK* (Dearden and Becker, 2004, YCRG).

LINK



Young Carers in the UK 2004 report



Potential impacts on young carers

- There may be problems at school, with completing homework and getting qualifications.
- Young carers can be isolated from other children of the same age and from other family members.
- They may lack time for play, leisure, or sport.
- There may be conflict between the needs of the person they are helping and their own needs, leading to feelings of guilt and resentment.
- They may get a lack of recognition, praise or respect from others.
- They may feel that there is nobody there for them and that professionals do not listen to them.
- They may feel that they are different from other children.
- They may feel that no one else understands their experiences.
- They may have problems moving into adulthood, especially with finding work, living on their own and establishing relationships.
- Young carers may experience conflicting emotions, such as loving the cared-for person while resenting the burden of care; being proud of what they do as carers while resisting the restrictions made on their young lives. This may lead to the young person feeling guilty or confused and perhaps further isolated from their peer group.

LINKS



Positive aspects of caring



What do you do if you identify a young carer?



Positive aspects of caring

- It is important to note that young carers do not necessarily dwell on the negative impacts of caring. They may welcome the sense of pride they feel about their caring role and achievements. They may also benefit from a close family environment that is supportive and caring of each other.
- The experience of being a young carer has some positive elements. Young carers can be highly self-motivated multi-taskers, coping with and achieving at school whilst also undertaking a caring role.
- However, it is important that recognition of the positive impacts of care does not inadvertently encourage the continuation of inappropriate care taking place or lead to the caring becoming a cause for celebration and not action.
- A young carer's ability to cope and achieve must not be used to mask their need for support.

“Helping her is just part of life. I don't really remember it being any different.”
(Young carer)

“Young carers aren't born with extra abilities, we're no different from anybody else; we just learn to cope because we have to.”
(Young carer)

Why do children and young people take on caring responsibilities?

- Historically, young carers and their families have fallen through the gap between agencies and service provision, in particular, adults' and children's services.
- Some of the issues and factors that can lead to a child undertaking inappropriate levels of care are: the nature of the family unit, nature of illness and perception of need, service provision.
- The majority of these young people are caring because someone in the family has unmet care needs.
- When there is a person within the family needing care, the child may take on the role of sole or primary carer or may help other adults or siblings with caring tasks. Some choose to take on the task voluntarily, others are informally nominated as a carer and, in some families, it is demanded. The majority, however, just grow into the role.

"It's just something I do. It has to be done and there is no one else to do it."

(Young carer)

"It is important to remember that we don't become carers at a certain age. Often you're born into it and don't realise you are different to other people."

(Young carer)

Types of caring


The tasks undertaken by children and young people vary, according to the nature of the illness or disability, the level and frequency of need for care, the structure of the family, etc. A young carer may undertake some or all of the following:

- practical tasks such as cooking, housework and shopping;
- managing the family budget, collecting benefits and prescriptions;
- physical care such as lifting;
- personal care such as dressing, washing, helping with toileting needs;
- giving medication or physiotherapy;
- ensuring safety;
- looking after or “parenting” younger siblings;
- giving emotional support or worrying;
- interpreting (either because of a hearing or speech impairment or because English is not the first language of the family).

Whole family working – the first steps

For services to provide effective support for young carers and their families, it is vital that all those working with them begin with an inclusive, wide ranging approach that considers:

- the needs of the person in need of care (including any parenting needs)
- the child (including whether they are providing inappropriate levels of care either physically or emotionally)
- the whole family
- the five outcomes of *Every Child Matters*.

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Every Child Matters, the Children Act 2004 and the National Service Framework all commit to family orientated but child focused support.

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Whole family working – the first steps *continued*

- Recognise that the reasons that children undertake inappropriate levels of care may be complex and that to resolve them may require a multi-faceted approach.
- Agencies need to work together in partnership towards preventing children and young people having to take on a caring role to an unreasonable or unwanted degree, and to ensure their protection where necessary.
- There needs to be joint accountability from both adults and children's services in order to prevent children caring inappropriately and to enable holistic whole family working.

For more information about implementing the Carers (Equal Opportunities) Act 2004 for young carers visit the SCIE website.

LINK



Social Care Institute for Excellence (SCIE)








Parent with illness or disability

When a referral is made for an adult with a disability or illness, consider:

- Is there a child in the family (including extended family members) who may be helping to provide care?
- Have they been offered an assessment?
- What can be offered to help the whole family?
- Does the parent need support in their parenting role?
- Establish routine and coordinated procedures for the early identification of disabled adults with parenting responsibilities, with a view to addressing support needs at an early stage and prevent children caring at inappropriate levels which impact upon their own development and well-being.
- Consider how the Common Assessment Framework might help you to assess and provide for a young carer.
- Refer to **Key Principle 1**.

LINKS

-  [Assessment](#)
-  [Common Assessment Framework](#)
-  [Disabled adults with parenting responsibilities](#)
-  [Direct payments](#)
-  [Key Principles of Practice for working with young carers](#)







Consider increasing the use of direct payments to prevent children caring inappropriately and to meet any parenting support needs.

A child in the family or an identified young carer

When a referral is made for a child who is caring, consider:

- Is the family member for whom they are caring already receiving services?
- A 'young carer' assessment should trigger an assessment or review of the person who needs care.
- Is the child's school involved or aware of the family situation?
- Do they need a referral to a young carers service?
- Refer to **Key Principle 1**.

LINKS

-  Assessments
-  Young carers services
-  Common Assessment Framework
-  Why do children care?
-  Sibling carers
-  Loss and bereavement

Child with an illness or disability

When a referral is made for a child with a disability or illness, consider:

- As well as assessing the child with a disability ask is there another child in the family who may be helping to provide care?
- Does the family need additional support?
- What can be offered to help the whole family?
- Does the parent need support in their parenting role?
- Consider how the Common Assessment Framework, Carers (Equal Opportunities) Act 2004 or Children Act might help you to assess and provide for a young carer or other children in the family to reduce any levels of inappropriate care being undertaken by a child?
- Refer to **Key Principle 1**.



Key Principles of Practice for working with young carers



Practical steps and points to remember when consulting with families and providing services

- Meaningful whole family assessments need to be carried out to prevent children and young people taking on inappropriate caring responsibilities.
- Families may need access to known and trusted translators and advocates to fully participate in the assessment process.
- Remember it is not good practice to use children or other family members as translators for someone who speaks another language or for someone who uses sign language.
- Remember that a young carer may not necessarily be living with the person they are caring for or may not be directly related to them.
- Use the Common Assessment Framework to log information and concerns in order to prevent families needing to repeat their needs to many different professionals.
- Use Family Group Conferences to resolve conflicts of opinion between parents and children as to what is an acceptable level of care.
- Be aware of both the social and medical models of disability.

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Assessment



Children as informal interpreters



Practical steps and points to remember when consulting with families and providing services *continued*

- Remember to consult with disabled adults about their parenting needs as well as their own care needs. Recognise that disabled adults have a right to have children and may need support to carry out their role as a parent.
- Be clear from the outset about the roles and responsibilities of health and social care practitioners in order to lower stigma and misunderstandings which prevent families from accepting support provision.
- Recognise the strengths and resourcefulness of families and not just their needs.
- Consider the times of day when meetings are booked and remember that children will be at school and cultural and religious reasons may result in people being unable to attend at certain times of the day.
- Remember families are the experts in their own lives and each family member should be consulted with.

Taken from *Supporting Disabled Parents and Parents with Additional Support Needs* (Morris, J and Wates, M, 2006, SCIE)

“When social services are knocking on your door you become very proud and you can cut your nose off to spite your face.”

(Disabled parent)

LINK



Supporting Disabled Parents and Parents with Additional Support Needs



Disabled parents with parenting responsibilities



Assessment




- An assessment of family circumstances is essential. Young carers should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances. It should not be assumed that children should take on similar levels of caring responsibilities as adults.
- Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities.

continued 

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.

(Key Principle 2)

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-  22 What should you think about before starting an assessment?
-  28 Disabled adults with parenting responsibilities
-  W Key Principles of Practice for working with young carers

What do you do if you identify a young carer?








Support for young carers needs to consider not just what tasks they are doing but the impact on their own well-being and development, and to ask **why** are they caring?

- A 'young carer' assessment should automatically trigger a community care assessment or review of the person who is receiving care.

- If it is suspected that the child may be in need of children's services or at risk of significant harm, under the Framework for Assessment under the Children Act 1989, adults' services workers should work in partnership with children's services to identify why this is so and whether additional support to the cared-for person could address the needs of the young person.
- Refer to local young carers services.
- **Think proactively...**

continued 

LINKS


-  What is a community care needs assessment?
-  Legislation and Guidance
-  What should you think about before starting an assessment?
-  Support for young carers
-  Multi-agency working
-  Local young carers services
-  Key Principles of Practice for working with young carers

If a child is caring inappropriately and the family refuses help, it may be necessary to refer to children's services for an assessment as a child in need or at risk.

(see Key Principle 1)

What should you think about before starting an assessment?

- Is the venue and timing suitable for the whole family?
- Think about who should attend – are there extended family members that should be involved? Will the children be able to attend or will they be at school?
- A person in this family may be entitled to an assessment under the Carers Act or Children Act.
- Explain to the family what the assessment is about including expectations, entitlements and outcomes.
- Do all the participants understand what is happening?
- Do they understand that they are entitled to request an update?
- Am I the right person to carry out the assessment and does anybody else need to be contacted and involved?
- Has the family seen the paperwork prior to the assessment so that they have time to prepare as well?
- Think outside the box – how can we extend choices and independence?
- Aim to highlight not just what caring tasks the children are doing but also why they are doing them.
- What are the expectations of the person/ organisation that referred that family? What are the expectations of the family?
- Be clear about the purpose of the assessment and don't build up false hope.
- Don't make assumptions about people's willingness or ability to provide care for another family member.
- Should there be differences of opinion between the adult and child during assessment, there should be an agreed protocol to settle these disputes. Family Group Conferences can be useful in assisting this process.
- Refer to **Key Principle 2**.

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LINKS



Family Group Conference



Key Principles of Practice for working with young carers



What is a community care needs assessment?

By law, every disabled person has the right to ask Social Services to assess their need of services.

The aim of the services should be to help disabled people to live independently and in their own homes wherever possible. There is Department of Health guidance to local authorities regarding assessing disabled people's needs and how to make sure that those needs are met. Fair Access to Care Services (FACS) guidance states that any needs that a disabled person has as a parent should be thought about as part of community care assessment.

“When doing an assessment it is important to understand how the condition or illness can affect the whole family and how families needs and individual's needs may differ but also affect each other.”

(Young carer)

The assessment should think with the disabled person, not just how things are at the moment but also what might happen in the future if services are not provided. Social Services are asked to assess the risks to the disabled parent's independence, health and safety if services are not provided. In the same way, the assessment should look at any risks to children, other family members and anyone who is helping a disabled parent if services were not provided. They should think about this for the short-term and for the longer term too.

(Disabled Parents Network, 2005)

LINKS



Fair Access to Care Services (FACS) guidance



What does a community care needs assessment involve?









What does a community care needs assessment involve?

A community care assessment should look at the different areas of a disabled person's life. As well as looking at any health care personal needs, it should look at social roles such as parenting or looking after relatives. It should think about the things that a person enjoys doing and the things they would like to do. It should cover paid and unpaid work, money and transport, holidays, education and training needs.

Assessment should look at a range of wider factors that affect family life, including where the disabled person is living, who they live with, whether the housing is properly adapted so that the parent can carry out their role, who does what within the family to help, whether this is working well or needs to change.

LINKS

-  Fair Access to Care Services (FACS) guidance
-  Health and social care assessments
-  Housing
-  Housing adaptation
-  Episodic illness
-  Family Group Conference

The assessment should:

- Be carried out by trained staff.
- Be at the right time - before crisis point.
- Be culturally sensitive.
- Involve the whole family.
- Recognise that all families are different.

Timely effective assessments of both the person who needs care and the whole family could prevent a child undertaking inappropriate levels of care in the first place.

A Family Group Conference may assist this assessment process.

Review, monitor and evaluate

Remember:

- Needs change
- There may be differences of view between children and parents about appropriate/ inappropriate levels of care. Such differences may be out in the open or concealed.
- The resolution of such tensions will require good quality joint working between adult and children's social services as well as co-operation from schools and health care workers.
- Assessments should include all young people within the family in order to understand their own perspectives and opinions.
- Refer to **Key Principle 2**.

The importance of signposting




It is important to remember that young carers and their families may have other support needs aside from their disabilities or caring responsibilities that impact upon the whole family or their ability to effectively support each other.

The needs of children and young people should be considered as part of the whole family and not separated.

Remember to signpost to appropriate services if other needs are highlighted.

When assessing a person for Community Care support, the impact of that package on children in the person's family should be considered. It is not acceptable to offer a community care package that depends on a child carrying caring responsibilities that are inappropriate to their role.

LINKS

-  More information about other services
-  Episodic illness
-  Key Principles of Practice for working with young carers

Health: the role of health and social care agencies

Health is likely to be the first agency that a family turns to for help with an illness or disability.

(Frank 2002)

The role of social care agencies

Adult services and other health and social care agencies need to be accountable and have a key role to play in preventing children from caring at inappropriate levels.

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

“Awareness-raising and the identification of young carers is an ongoing task and there must be strategies in place to deliver a rolling programme of training to all those who work directly with young carers and their families.”

(Key Principle 5)

The role of the health service

Although social services departments have a key role to play in supporting young carers and their families, they may not be the key agency for initially identifying needs. The National Strategy for Carers (DOH 1999c) states that GPs and other primary care staff, in particular, can provide valuable, sensitive support to young carers and their families.

LINKS



What do you do if you identify a young carer?



Housing



The National Strategy for Carers (DOH 1999c)



Multi-agency working



Key Principles of Practice for working with young carers



Supporting young carers and their families: information for health care professionals



Common Assessment Framework (CAF)

The CAF is a nationally standardised approach to conducting an assessment of the needs of a child or young person and deciding how those needs should be met. The CAF will promote more effective, earlier identification of children's additional needs and improve multi-agency working. It is intended to provide a simple, non-bureaucratic process for a holistic assessment of a child's needs, taking account of the individual, family and community.

The DCSF has commissioned the development of training materials to support the implementation of the CAF.

Single Assessment Process (SAP)

The single assessment process, introduced in the NSF for older people, aims to make sure older people's care needs are assessed thoroughly and accurately, but without procedures being needlessly duplicated by different agencies.







Information sharing

Better information sharing and multi-agency working, coupled with new tools and processes, such as the Common Assessment Framework (CAF), the lead professional role and Contact Point, previously known as the information sharing index, are helping to deliver effective services for children, young people and families.

"My daughter has been contacted by twenty-nine professionals in her life!"

(Disabled parent)

LINKS

-  [Common Assessment Framework](#)
-  [CAF training materials](#)
-  [Single Assessment Process](#)
-  [Information sharing](#)
-  [Lead professional](#)
-  [Contact Point](#)

Disabled adults with parenting responsibilities

“I used to play football with them on Saturdays. Now I can’t even get down the hill to watch.”

(Disabled parent)

Ill and disabled parents need to be supported in their parenting role.

Establish routine and co-ordinated procedures for the early identification of disabled adults with parenting responsibilities, with a view to addressing parenting support needs at an early stage. (Refer to Key Principle 2.)

Disabled parents have the same human and civil rights as non-disabled parents. For more information see the Disabled Parents Network website.

“Since the accident, she’s changed... she’s just not my mum any more.”

(Young carer)

LINKS



Housing



Disabled Parents Network



Rights legislation and disabled parents



What disabled parents have said good services should cover



A checklist for good practice



Direct payments



Key Principles of Practice for working with young carers



Equipment and disabled parents



Disabled parents and school



Transport



Supporting disabled parents and parents with additional support needs

Disabled parents have said that good services should:

- be offered in time to prevent unnecessary difficulties.
- include fathers as well as mothers; grandparents and other kinship carers, foster and adoptive parents, as well as natural parents.
- respond flexibly and quickly to changes in family situations.
- be responsive to cultural needs and preferences.
- provide access to parenting support without the automatic involvement of children's services.
- not leave family needs unmet because they fall between administrative categories.
- not pass parents between agencies and service divisions to avoid cost.

(Morris, J. and Wates, M. 2006, *SCIE Knowledge Review*)

continued 

LINK



SCIE Knowledge Review



Disabled adults with parenting responsibilities: A checklist for good practice

- Are disabled adults (including parents with physical and sensory impairments, Deaf parents, parents with learning difficulties, those who are users of mental health system and those with drugs and alcohol issues) recognised as service users with support needs in relation to parenting?
- Is there clear agreement about how Community Care legislation in combination with children's legislation where appropriate, is to be used to support disabled parents and families?
- Where policies/protocols/procedures exist, are they in use and are all staff and relevant bodies aware of what they say?
- Are parenting tasks and responsibilities included in eligibility criteria and covered in assessment procedures for adult services and benefits?
- Is the meeting of needs associated with parenting responsibilities regarded as a priority for access to assessment and service allocation?
- Are mechanisms in place that ensure timely and effective cross-referencing between different agencies and across organisational divisions to ensure that disabled adults with parenting responsibilities are effectively keyed in to mainstream and specialist supports?
- Do support systems have the flexibility and responsiveness to respond quickly and appropriately to changing family needs?
- Do policies and protocols ensure that no disabled parents should be obliged to rely upon a family member for inappropriate levels of assistance or for help with inappropriate tasks?

(Olsen & Wates, 2003)

LINK



SCIE resource: *Working Together to Support Disabled Parents*



Use direct payments to meet parenting support needs

If an adult qualifies for services they may be offered direct payment.

Direct payments may be used to support parenting and can be paid for by both adults' and children's services. Direct payments can also be given to adults who have taken on informal caring roles for people who are entitled to community care services.





Information for families

Information materials should be understandable and made available in appropriate formats and languages. The information given should be simple, relevant, accessible and accurate, so families know what services are available and are able to make informed choices. Service providers should take reasonable steps to make information available to those who need it.

“A couple of friends gave me a little advice, then it was a question of taking each day as it comes and hoping for the best.”

(Disabled parent)

LINKS

-  Disabled Parents Network information briefings: For families
-  Direct payments
-  Benefits
-  Direct payments information briefing

Benefits

It is important that disabled parents should be able to get hold of good information and advice about money. This includes any benefits and grants that could be available to them.

Information for families from the Disabled Parents Network

The Disabled Parents Network has produced information briefings for parents aiming to bridge the gap between information about parenting and information about disability. They provide information about disabled parents' legal rights and explain how to get your parenting needs assessed and met, what to do if you are not happy with services, how to find legal help when it is needed and some of the other support available to parents.

This includes information regarding:

- Legislation
- Services and practical matters such as equipment, housing, transport and holidays
- Assessments
- Care plans
- Direct payments
- Maternity services and new parents
- Complaints
- Advocacy, advice and legal help.

These briefings are free to disabled parents.

LINK



Disabled Parents Network briefings



Children with disabilities

The Children's Society Disability Toolkit

Your first step when involving disabled children and young people in decision-making and participation.

LINKS



The Children's Society Disability Toolkit



Points to consider on referral of a child with ill-health or disability

For families who have children who are disabled or ill

In common with parents who themselves have care needs, parent carers need timely information about their child's condition, information on how to access an assessment of need, and information on the range of services available to support their child and themselves in their caring role. The assessment should recognise and monitor any needs of siblings who may be helping to care, in order to ensure that the service package to the family takes account of the needs of all members of the family.

Brothers and sisters

Some children and young people give significant practical and physical help to siblings who are disabled or chronically ill. Many find themselves with the responsibility of ensuring their safety and supporting their other needs, for example, where a brother or sister has a learning disability. Others give significant emotional support to their parents and siblings.



Loss and bereavement

Loss

Young carers may experience a sense of loss in a number of ways, which may need support and understanding. This is also true for the person in need of care and other family members.

Bereavement

Some young carers may face and experience bereavement, and their needs for information and support may need to be met by an appropriate agency, both pre- and post-bereavement.

Refugee children

Unaccompanied refugee children caring for siblings or friends could be suffering with a great deal of trauma and loss.

LINKS



Young Carers and Bereavement leaflet



Young Carers from refugee communities



Education

“Young carers will have the same access to education and career choices as their peers.”
(Key Principle 4)

Setting up support for young carers in school

It is strongly recommended that before schools begin to raise pupils’ awareness of the issues relating to carers, they ensure that support measures are in place. It is possible that by introducing the subject, some pupils will be considering issues relating directly to themselves for the first time. Also some pupils will want and will need to see support that is readily accessible.







When providing support to young carers consider the impacts of their caring responsibilities.







Don’t forget there are positive impacts of caring!

“Every school will have young carers ... and just one individual teacher or support worker being involved can make a huge difference.”

(Young carer)

LINKS

-  Key Principles of Practice for working with young carers
-  Support for young carers within school
-  The impacts of young carers’ caring responsibilities
-  Positive aspects of caring
-  Identifying young carers in school
-  Young carers’ suggestions for schools

-  Transport to school
-  Legislation and guidance for supporting young carers in school
-  Schools notice board
-  Supporting pupils who are young carers: information for teachers
-  Education welfare and young carers
-  Educational support and other agencies





Identifying young carers in school

It is possible that the school will not know formally that one of the pupils is a young carer. This could be for several reasons:

- Children often do not want or feel able to confide that they are caring and that they need extra help and consideration.
- They may not want to appear to be different or may not be aware that they can ask for help.
- They may be embarrassed about their home situation, particularly if they are caring for someone with alcohol dependency, substance misuse, mental ill-health or a learning disability.
- They may wish to forget about responsibilities and see school as an escape.
- They may fear teasing or bullying and have a fear of interference or change that may result in the family being split up.
- The young person may not consider themselves to be a young carer, especially if their responsibilities at home have developed over time.
- The degree of caring may alter according to family need.
- The nature of the cared-for person's illness may mean that the young person's caring role is episodic.

It is important for schools to raise awareness among pupils and staff about the issues relating to young carers in order to allow them to access support if they need it without having to identify themselves as young carers, e.g. by using a schools notice board.

LINKS

-  Signs that may indicate that a child is caring for someone at home
-  Benefits to identifying young carers in school
-  School notice boards
-  What do you do if you identify a young carer?

Signs that may indicate that a child is caring for someone at home

There are some common signs that may indicate if a child is undertaking inappropriate levels of care at home.

- Arriving late at school
- Unable to complete homework on time
- Difficulty concentrating in class
- Behavioural difficulties
- Missing school/need to take days off
- Tiredness/fatigue
- Withdrawn, over-sensitive
- Clothing or appearance may not be clean or tidy/lack of self-care
- Low self-esteem
- Underachieving
- Ill health e.g. stress-related illnesses, back problems from lifting, anxiety, depression
- Have few friends/have difficulties in mixing with peers
- Have difficulty attending after-school activities and in attending school trips (e.g. residential)
- Being bullied
- Some parents are unable to have contact with school – maybe missing parents evening, for example
- Financial difficulties
- Reluctant to discuss home circumstances.

(Frank, 1995)

“I don't want to be different. I am worried they will tease me again about mum and the way she is ... so I just keep quiet.”

(Young carer)



Benefits to identifying young carers in school

Action on the part of schools to support young carers can:

- help to increase and maintain levels of school attendance
- promote attainment of a child's full personal and academic potential, which will itself raise the overall achievement levels of the school.
- increase the understanding by school staff of the young carer's circumstances and may provide an explanation of the child's behaviour.

"I would love to tell the school – there's some mornings when I'm so tired and my child will then be late for school. It would be good if I knew the teachers wouldn't pick him out and tell him off for being late."

(Disabled parent)

"Identifying young people with caring responsibilities for a relative at home is difficult – they may not have the language, confidence or self-awareness to relay the physical and/or emotional impact of living with a relative who requires care, let alone identify themselves as having caring responsibilities."

(Baker, PRTC, 2002)



Support for young carers within school

- **Connexions** provides a network of personal advisers who will be able to offer advice and support to young carers and put them in touch with appropriate specialist and support services. Priority will be given to those young people who are at risk of not making an easy transition to adulthood.
- **School counselling** Counselling in schools can offer a significant level of support to children with emotional and behavioural difficulties. Bereavement, loss, relationship difficulties, anxiety and bullying are major issues that can lead to deterioration in a pupil's behaviour, attitude and mental health.


“I think that schools should talk to you more about what's going on at home.”

(Young carer)

“The carers centre has really helped me to calm down and have fun. The school should know more about other people who can help young carers so they can work with them.”

(Young carer)

- **Educational psychology** School staff may consider referring a young person to the Educational Psychology Department for an assessment if they consider a young person is experiencing learning difficulties. When a referral is made to an educational psychologist include any details about the young person's caring responsibilities, which may impact on their learning. Educational psychologists will want to explore any circumstances at home that may be impacting on the child's learning ability. If they engage with parents, they will also need to take in to account any special needs of the parent(s) which could prevent them from attending assessment meetings.

continued 

LINKS



Connexions



Educational psychology



Careers



Disabled parents and school



Support for young carers within school *continued*

- **Education welfare teams** School staff may consider consulting education welfare about providing support for a young carer who is finding it difficult to attend school
- **Behaviour and Education Support teams** promote emotional well-being, positive behaviour and school attendance, by

identifying and supporting those with, or at risk of developing, emotional and behavioural problems. A referral could be made to these teams if school staff are concerned for a young carer who is having difficulties settling at school.





“I missed a lot at school because he wasn’t well and I didn’t like leaving him in case he fell over and couldn’t reach a phone or pull the cords ... I went to it twice a week, that was it.”

(Young carer)

“I get stressed with what is going on at home and take it out on the teachers. They give me detention and send me out of class, they don’t understand.”

(Young carer)

LINKS

-  Education welfare officer
-  Education welfare good practice
-  Behaviour and Education Support teams
-  Young carers affected by substance misuse in school

Education Welfare Good Practice guidance

- If a young person is routinely absent from school, consideration must be given to the health status of a relative at home to whom that young person may be providing care.
- Young people may be feeling anxious to go to school and guilty about leaving the person they care for, because of their care needs.
- Childcare responsibilities for young siblings and/or the absence of assistance to the parent in transporting their child to school must also be taken into account when working with young carers who are frequently absentees.
- Consider providing home tutoring to pupils clearly unable to attend school as a result of their caring responsibilities.
- Ask the parent(s) what support/and services they would like to access, to enable their child to return to school and to help ease the level of care given by their child to a relative at home.
- The longer a child is absent from school, the more anxious they may feel in returning to school because of the concept that they have as to how far behind they may be with their studies in comparison to their peers.

continued 

“I used to run away from school because I wanted to be with my mum. I used to think my mum was going to die. I was about eight.... They treated me as if I was playing truant.”

(Young carer)

Education Welfare Good Practice guidance *continued*

- Ask the child what support they would like to receive from their school that may help them feel more confident in returning to school.
- Remember to ask if the child would feel less anxious leaving the person for whom they cared, if they were given access to a telephone during the day.
- Ask the parent(s) and child if they can identify a teacher who can be given details of their caring responsibilities at home.
- Liase with the young carer's school, and ensure that the school has simple policies in place for supporting young carers returning to school after a period of absence.

Source: Frank, J. (2002) *Making It Work, Good Practice with Young Carers and their Families* The Children's Society.

“They need to understand just how much we have to do from the time we get up to the time we go to bed.”

(Young carer)

- Education Welfare Teams should liase with the parent(s) and child(ren), the school and local young carers project at an early stage.
- An Education Welfare Team could then call a multi-agency meeting if needed if required to consider appropriate support for the whole family.

LINKS



Multi-agency working



Making it Work



Education Welfare Officers








Education support for young carers from other agencies

Your Local Education Authority and agency policies (e.g. Education Welfare Officers, Educational Psychology, Education Other Than At School (EOTAS), Youth and Career services) should also include provision for young carers and have an inter-agency strategy to support them.

“School staff may be the first to be aware of the young person’s caring situation, and therefore be key to setting the tone for the service response and trigger inter-agency action.”

Department of Health

LINKS

-  Local Education Authorities
-  41 Education Welfare Officers
-  39 Educational psychology
-  Educational Maintenance Allowance
-  DCSF Circular: Pupil Support

School nurses

School nurses can also play an important role in supporting young carers in schools. Some school nurses are based permanently within schools and are ideally placed to support young people, particularly given their knowledge of the care needs of those with medical conditions and disabilities.

Educational Maintenance Allowance

(EMA) is a weekly payment for eligible students on further education courses; EMA is intended to help with the day-to-day costs if a young person stays on at school, college or training provider – such as travel, books and equipment for the learning programme.

School notice boards

Young carers have expressed the need for a notice board in their schools displaying up to date information including:

- support and resources in their community for young carers and their families
- community projects, including a young carers project, in the local area.

A notice board in school can help identify and support young carers.






The Children's Society has developed a notice board and a leaflet to be used in school.

Careers

“Many young carers have key skills and competencies that go unrecognised and there is currently no way of accrediting such skills... While the acquisition of such will not be best achieved by caring unsupported, such skills, if acknowledged would be an asset to many employers.”

(Dearden and Becker, 2000b)

LINKS

-  School notice boards
-  Resource pack for schools
-  Connexions Direct/careers
-  Supporting pupils who are young carers: information for teachers
-  School and College: Moving on

Transport to school

“Local authorities may take into account a parent’s capacity to accompany their child on the journey to school. It is for individual authorities to make decisions on these matters and social services should play their part in supporting disabled people to fulfil their responsibilities as parents.”

(Key Principle 4)

“It would help if my children’s school knew and therefore understood the consequences of the illness. For example, there are times when it’s difficult to get the kids to school – when I have hospital appointments, when I’m too ill.”

(Disabled parent)

LINKS



Transport to school



Key Principles of Practice for working with young carers






Young carers' suggestions for schools

- Recognise that our responsibility as carers can affect our education and schoolwork.
- Find out about us, what we need and how we are not like other students.
- Take time to find out about individual problems at home. Sometimes we're too embarrassed to tell you ourselves.
- Don't automatically punish us if we're late. Sometimes we can't help being late because we're helping out at home.
- Provide more support such as lunchtime drop-ins or homework clubs.
- Be flexible - give us more time and help to do homework or coursework.
- Include information about young carers and disability issues in PHSE lessons.
- Let us phone parents if we need to find out if they are OK.
- Make sure there is a clear and up to date community notice board which has support information for us and where else we can get help in the community.
- Ensure teachers are offered training on young carers and disability issues both at university and on inset days.

(Young carers at the Young Carers Festival 2006)

LINKS

-  Young carers and bullying
-  Anti-bullying organisations
-  Young Carers Festival

Legislation






In autumn 2005 the Government published the Schools White Paper *Higher Standards, Better Schools For All*, a major step forward in the Government's aim of ensuring that every child in every school in every community gets the education they need to enable them to fulfil their potential. Many of these changes do not require legislation; others are taken forward by the Education and Inspections Act. The Act also includes some provisions which were not included in the White Paper.

DCSF Guidance: Behaviour and Attendance in School

- Refers to possible lateness or absence of young carers because of their responsibilities. It suggests that schools should set time limits for absence and set some schoolwork.
- Referrals to outside agencies should be handled sensitively.
- Schools should consider designating a member of staff to have responsibility for young carers.
- Schools can contribute to support schemes.

The new DCSF guidance to schools *Advice and guidance to Schools and Local Authorities on Managing Behaviour and Attendance: groups of pupils at particular risk* recommends designating a lead member of school staff for young carers.

LINKS

-  White Paper: Higher Standards, Better Schools for All
-  Education and Inspections Act
-  DCSF Behaviour and Attendance Guidance
-  DCSF School Attendance: Tackling it together
-  Other legislation and guidance relating to young carers and their families

Diverse communities and support

“The social worker told me there was an Asian carers support group up the road. I got there and none of the carers spoke English – or my language. But actually I was looking for somewhere I can discuss things that affect everyone, mix with others not just Asians.”

(Carer from Asian family)






Many Black, Asian and other minority ethnic families, including Gypsies and Travellers and EU migrants, are already isolated from services. The majority of people of Black and Asian origin in Britain were born here, and in some places no longer form a minority of the population, but still experience a lack of support to meet their specific cultural needs.

Carers from BME communities mostly have the same needs as others. However, culturally sensitive ways of enabling people to access services are needed, and some services may need to adapt the way they are provided to meet the needs of particular communities. Different communities are likely to require different approaches to meet the same needs.

Ensure that all staff have appropriate training in cultural competence and can demonstrate at least a minimum understanding of the personal care and social care needs of the communities they are working in. However do not assume that all families from a particular culture will have the same needs.

The Afiya Trust (2008)

LINKS

-  Traveller and Gypsy families
-  The Afiya Trust
-  Housing
-  Family Inclusion Project
-  Refugee and asylum seeking families

Refugee and asylum seeking families

- Refugee and asylum seeking families can face barriers to health and social care support, including language and cultural differences, that need to be met in order to adequately meet the needs of these families. It stands to reason that with these barriers care needs will be missed when undertaking assessments and providing support. This can adversely fall upon other members of the family, including children, or local community with detrimental effects.

“We end up becoming translators, legal advisors, housing advisors and carers for the whole community.”

(Young carer with refugee status)





Children as informal interpreters

- Insufficient translation services can result in the responsibility for interpreting falling to other family members. The use of family, friends and other community members as informal interpreters should be discouraged as it denies patients the right to confidentiality within their family or community.
- Children should not be expected to be translators of inappropriate information, including health and social care assessments, for their parents as this can be detrimental to their own well-being. It can also impact upon their school attendance if they are attending meetings with their parents.

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

(Young carer with refugee status)

LINKS

-  [Leading Edge young refugees schools project](#)
-  [Resources for working with refugee and asylum seeking families](#)
-  [Young carers in refugee and asylum seeking families](#)
-  [Children as informal interpreters](#)

Housing

- *The key to change is the development of a whole family approach and for all agencies to work together.*
- *Recognise what environmental factors are having an adverse effect on the family, including housing, availability of local transport or shops.*

(Key Principle 4)

LINK



Key Principles of Practice for working with young carers



Housing adaptation



Housing Act 1996

Priority housing need

Section 189(1) of the Housing Act 1996 states that an applicant will be accepted as having a priority need for housing if any of the following apply:

- The applicant is a person with whom dependent children reside or might reasonably be expected to reside.
- The applicant is vulnerable as a result of old age, mental health or handicap or physical disability or other special reasons, or with whom such a person resides or might reasonably be expected to reside.

Good practice points for housing allocation

- The needs of the Whole Family should be taken into account when being allocated housing.
- The housing needs of families should be taken into account when dispersing families under the Immigration and Asylum Act 1999.

“When we moved I had a frustrating few months as the new home was being adapted. I felt as though I’d got worse but I had not really - it was because nothing was right in the house.”

(Disabled parent)



Nature of illness and disability

“It would help if someone could be there when we actually need them ... when things get out of hand.”

(Young carer)

Sensory impairments

Ensure that the needs of anyone with a sensory impairment are considered so that they have information about processes and services available in appropriate formats so that they can make well-informed choices and do not need their children to interpret for them.

Episodic illness

Caring needs vary according to the nature of an illness: whether it is a stable, managed condition, or degenerative, or periodic. Periodic episodes and relapses can occur with both physical conditions (e.g. MS, arthritis) and also with mental ill-health or substance misuse.

Mental ill-health

Mental illness is often episodic. The situation at home can fluctuate from a normal secure home life to periods of instability, confusion and emotional upheaval. Changes in the behaviour of parents with mental ill health can be traumatic for the children, and all the more so if they are trying to take on some or all of the caring responsibilities. Children caring for a parent with mental ill health can feel a great sense of responsibility and loyalty to their parent and some go to great lengths to conceal the illness and its effects and to make up excuses for their behaviour.

Assessments need to take into account that needs can change.







Substance misuse and alcohol

Here the roles of child and parent can become confused and these children may feel they are responsible for their parents' behaviour and mood changes. As a result, they may develop intense feelings of guilt. They may be afraid of what happens at home becoming public knowledge, which may lead to them becoming isolated from other children or they may mix with older children who are problem drug-users themselves. Some children may have inappropriately high levels of responsibility for the social or personal care of parents with problem substance-use or for the care of siblings.

Many young carers projects support children caring for someone who misuses drugs or is dependent on alcohol. They often work with local specialist agencies to provide support to both child and family. Remember that many of these families and children will feel anxious about revealing their problems and taking the first steps to seeking help.

continued  53

LINKS

-  Young carers and substance misuse in school
-  Parents and substance misuse
-  Working Together to Safeguard Children 2006
-  DATs and the National Drugs Strategy

Working Together to Safeguard Children 2006 responded to the Advisory Council on the Misuse of Drugs by recognising the impact that parental drug misuse can and does have upon children throughout each stage of development. It calls for a thorough assessment to determine the extent of need and the level of risk of harm in each case, calling for local Safeguarding Boards to take full account of the complexities and challenges of this area of work and requiring them to have in place:

- Local Safeguarding Board policies and Procedures.
- Interagency Protocols for the co-ordination of assessment and support particularly across adult drug services and children and young people's services.
- Close collaboration with local DATs (or DAATs) and other agencies that can assist in the assessment and outcomes.

Blood-borne viruses (including HIV/AIDS)




Children who have parents with blood-borne viruses (including HIV) will need sensitive and specialist support. Families will need support so that the child does not undertake inappropriate levels of care.

The particular nature of the illness, associated stigma and need for confidentiality may compound to hide the level of caring that a child is undertaking, particularly at an emotional level.

“People think you are to blame for having HIV. It’s because you’re African, or they think you’re a prostitute or use drugs.”

(Parent with HIV)

LINKS

-  Young carers and HIV/AIDS: Messages for policy and practice
-  Children and young people’s HIV network
-  Young carers and HIV

HIV/AIDS: Messages for policy and practice

- There is a need for greater recognition of children's caring responsibilities in families affected by HIV from the local to the global level, and the development of policies, services and support to meet the specific needs of this group of young carers, within the broader category of children affected by HIV/AIDS/orphans and vulnerable children.
- Key approaches that promote resilience include practical and emotional support for parents with HIV, holistic family approaches, opportunities for short breaks, social activities with other young people in similar situations and the development of life skills. Confidentiality, cultural appropriateness and sensitivity to stigma and diverse, complex needs are paramount to the development of services for children and parents with HIV.
- Linked to this is a need for greater awareness and knowledge of HIV/AIDS within families, communities, schools, governmental and civil society organisations and welfare institutions. This would reduce stigma and discrimination, enable children and parents to seek support and help to prevent and alleviate children's unpaid care work in families affected by HIV/AIDS.

Evans, R. and Becker, S. (2007)

LINKS



Hidden Young Carers



Support for young carers

“Local young carers projects and other direct services should be available to provide safe, quality support to those children who continue to be affected by any caring role within their family.”

(Key Principle 6)

Local young carers projects and other direct services





Local young carers projects and other direct services should be available to provide safe, quality support to those children who continue to be affected by any caring role within their family.

Young carers projects have a wealth of expertise about young carers' issues and local needs. Evaluations have shown that the support and activities provided are greatly valued by both the children and their families, for whom they are often the only or main source of support.

Projects can also play a key role in raising awareness, offering training and identifying gaps in services, not just for young carers but also for the person in need of care and for other agencies that offer services.

Young carers projects and other direct services provide sustained safe environments for children and parents to contact for information and support. They promote and protect the physical and mental well-being of young carers, providing a child-focused but preventative 'whole-family' approach and working in partnership with other agencies, including schools.

LINKS

-  Find a young carers project
-  Key Principles of Practice for working with young carers
-  What is your Local Authority doing for young carers?
-  56 Emotional support and help for young carers

Emotional support and help for young carers

- Caring has a high emotional element for the children. Many have described the worry and anxiety that they experience when someone who is close to them is ill or disabled. Those who do not give any practical or physical care may still be giving emotional support, and experiencing a range of emotions, anxieties and stress. Young carers projects can offer support to young people with caring responsibilities.
- Child and Adolescent Mental Health Services (CAMHS) are a comprehensive range of services available within local communities, towns or cities, which provide help and treatment to children and young people who are experiencing emotional or behavioural difficulties, or mental health problems, disorders and illnesses.

“I feel really guilty if I talk about her... So I keep it inside and it becomes a big secret. But then I snap and people don't know why. It's very difficult.”

(Young carer)

“It's not just the caring that affects you... what really gets you is the worry of it all.”

(Young carer)

LINKS



CAMHS



Young carers projects



Recommendations for supporting the emotional well-being of young carers



Recommendations for supporting the emotional well-being of young carers

Information provision

- Promote more open discussion and provide accessible 'family friendly' literature about mental ill health and how to access help.
- Inform children about family illness and changes to routine and circumstances at levels appropriate for child's age and understanding regardless to whether they are caring or not.
- Offer training and support to young carers workers in listening skills so that they can continue to be a source of support but also know when to refer a young person onto another agency.

Peer support

- Consider monitoring and evaluating the peer support provided by groups to inform other models of support.

Timely whole family support

- Work with the family to support them in talking about and coming to terms with illness, if needed. Offering timely, well-structured and

flexible support to the person in need of care could prevent a child undertaking inappropriate levels of care.

Coping strategies

- Consider what coping strategies might help children and families deal with any stigma they feel or experience.

Working with other agencies

- Counselling and child psychiatric agencies, including CAMHS, could consider linking with young carers projects so their role is better known and understood by young carers therefore building elements of trust.
- Consider how to work with schools, and with media, to identify ways to promote more understanding about mental illness in order to begin to reduce stigma.
- Work with schools to promote understanding of the emotional needs of young carers.

(Taken from 'Emotional Support for Young Carers'. The Children's Society and The Princess Royal Trust for Carers, published by The Royal College of Psychiatrists).

LINK



The Royal College of Psychiatrists and The Princess Royal Trust for Carers Mental Health Factsheets



Legislation and guidance

There is a range of legislation and guidance which may be used to support young carers and their families.

All practice with young carers should consider whether they are achieving the Specific Outcomes from Every Child Matters:

- Be healthy
- Staying safe
- Enjoy and achieve
- Achieve economic well-being
- Make a positive contribution.

- The Children Act 2004
- Every Child Matters
- Common Assessment Framework
- Children Act 1989
- Department of Health (2000). Framework for the Assessment of Children in Need and their Families Guidance
- The UN Convention on the Rights of the Child
- National Services Framework for Children, Young People and Maternity Services
- DCSF guidance: Behaviour and attendance in school
- Department of Health (2003). The Direct Payments guidance
- Caring About Carers. The National Strategy for Carers 1999
- Carers (Recognition and Services) Act 1995 S1
- The Carers and Disabled Children Act 2000
- Carers (Equal Opportunities) Act 2004
- Fair Access to care services (FACS) guidance

LINKS



LINKS



- National Health Service (NHS) and Community Care Act 1990
- The Disability Discrimination Act 1995 (DDA)
- Human Rights Act 1998
- Disabled Persons (Services and Consultation and Representation) Act 1986
- Chronically Sick and Disabled Persons Act 1970 Section 2
- National service framework for Mental Health 1999
- Fair Access to Care practice guidance (DH 2002)
- A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role (Department of Health, 2000)
- Valuing People: A New Strategy for Learning Disability for the 21st Century
- Health and Social Care Act 2001 (section 58) amending for Children Act 1989, section 17 re Direct payments in respect of children
- Section 189(1) of the Housing Act 1996
- Social Services Inspectorate 1995 Young carers: something to think about
- Social Services Inspectorate - Young Carers Making A Start
- The Data Protection Act 1998
- DH 1991 Care Management and Assessment: Practitioners Guide

Resources for young carers and their families

Information should be provided to families that explains their entitlements and how to access support and services.

Government organisations

- **Related SCARE briefings from Social Care Institute for Excellence (SCIE)**
 - The health and well-being of young carers
 - Helping parents with a learning disability in their parenting role
 - Helping parents with a physical disability or impairment in their parenting role
 - Parenting capacity and substance misuse
- **Connexions** Offers information and advice for 13–19 year olds on a wide range of topics as well as confidential advice and practical help.
- **Department of Health** Information for teachers on health; with links to sites for different age groups.
- **Directgov** A portal to public services information including disability and caring.

Voluntary organisations

- **The Children's Society Include project**
- **The Princess Royal Trust for Carers**
- **Disabled Parents Network**

LINKS



For families

- **Riprap** For when a parent has cancer. An interactive site for children and young people to find out more about cancer and share their experiences with others in their situation.
- **Family Rights Group** Provides advice and support for families whose children are involved with social services and develops and promotes services that help secure the best possible futures for children and families.
- **The Disability Law Service** A national registered charity that provides confidential and free legal advice for disabled adults, their families and carers. DLS also provides disabled people with a casework service.
- **The Equality and Human Rights Commission** The aim of the Commission is to end discrimination and harassment of people because of their disability, age, religion or belief, race, gender or sexual orientation.
- **DIAL** A national organisation for a network of approximately 130 local disability information and advice services run by and for disabled people. Last year DIALs helped over a quarter of a million disabled people.
- **NHS Direct** Provides information and advice about health, illness and health services, to enable patients to make decisions about their healthcare and that of their families. The website also provides health information in other languages.
- **Citizens Advice Bureau** An online service that provides independent advice on people's rights.
- **Parentline UK** An online resource for support with parenting





For families *continued*

- **The British Council of Disabled People (BCODP)** Set up by disabled people in 1981 to promote full equality and participation within society. It is an umbrella organisation that represents some 130 organisations run and controlled by disabled people.
- **Ricability** Has produced leaflets on equipment for disabled parents.
- **Winston's Wish** An interactive site for young people who have lost someone close.
- **Disabled Parents Network information briefings** There are 10 information briefings available free for disabled parents to inform them of their rights and entitlements:
 - 1 An introduction to the briefings
 - 2 What the law says
 - 3 Services
 - 4 Getting your needs assessed
 - 5 Making a care plan to meet your needs
 - 6 Direct payments and disabled parents
 - 7 Maternity services and support for new parents
 - 8 Making a complaint
 - 9 Advocacy, advice and legal help
 - 10 Contacts and publications





Diverse communities and support

- **Friends, Families and Travellers** Provides information and resources for gypsy and traveller families and those who work with them. The website includes information regarding health entitlements and access to services.
- **Language Line** Language Line Services is a global interpreting and translation company, it enables organisations to communicate effectively with people of all nationalities.
- **HARP: Health for asylum seekers and refugee portal** HARP provides social inclusion research and on-line health information for health professionals and voluntary agencies working with minority communities.
- **HARP: Mental Health and Well-being Resource** Provides a range of topics from a variety of sources relevant to the overall mental well-being of asylum-seekers and refugees.
- **Communicate** Provides multilingual and multicultural health resources including appointment cards
- **Medical Foundation for the Care of Victims of Torture** Offers free medical, psychological, emotional and social assistance to survivors of torture and organised violence and to their families. They also campaign against torture and similar human rights abuses.
- **Refugee Council Online** The Refugee Council is the largest organisation in the UK working with asylum seekers and refugees. We not only give direct help and support, but also work with asylum seekers and refugees to ensure their needs and concerns are addressed. This website provides multilingual information.
- **Refugee Action** Refugee Action has over 20 years experience in the reception, resettlement, development and integration of asylum seekers and refugees.





Bullying

- **Anti-Bullying Alliance** The Alliance brings together over 65 organisations into one network with the aim of reducing bullying and creating safer environments in which children and young people can live, grow, play and learn.
- **Beatbullying** Beatbullying aims to reduce and prevent the incidence and impact of bullying, (physical, emotional, verbal, genderised, racist, inter-faith, homophobic) between young people.
- **Bully Free Zone** Has become one of the leading peer support projects in Britain. The project aims to raise awareness of alternative ways of resolving conflict and reducing bullying.
- **Childline** The free 24-hour helpline for children and young people in the UK. Children and young people can call the helpline on 0800 1111 about any problem, at any time – day or night.
- **Connexions-Direct** Have information on bullying on their website
- **Kidscape** The first charity in the UK established specifically to prevent bullying and child sexual abuse.



Organisations working for young carers and their families

LINKS

-  www.youngcarer.com
-  www.childrenssociety.org.uk
-  Joint position statements on young carers from The Princess Royal Trust for Carers, the Disabled Parents Network and The Children's Society
-  Key Principles of Practice for working with young carers

The Children's Society, Include Project National Young Carers Initiative

The aim of the Young Carers Initiative (YCI) is to develop a coherent National Focus for young carers, their families and those who work to support them and to promote common standards and to work towards realisation of equitable services.

The Children's Society, National Young Carers Initiative is partly funded by DCSF and DH to provide information, advice and training to anyone who works with young carers and their families across England and the UK. We also offer information to Young Carers and their families.

The work is carried out in consultation with young carers and their families to develop good quality support and information for young carers, their families and those who work to support them.

The National Young Carers Initiative has developed Key Principles of Practice for working with young carers and their families.

The Disabled Parents Network

The Disabled Parents Network is a National network of Disabled Parents, helping each other and bringing about change for disabled people who are parents or who hope to become parents, their families, friends and supporters. The Disabled Parents Network welcomes all parents, including those with physical disabilities, sensory impairments, learning difficulties, long term illnesses, or mental health issues.




The Disabled Parents Network has developed information briefings for disabled parents, available on their website.

The Princess Royal Trust for Carers

The Princess Royal Trust for Carers is the largest provider of comprehensive carers support services in the UK. Through its unique network of 122 independently managed Carers' Centres and interactive websites, Carers.org and YC Net, information, advice and support services are provided to almost a quarter of a million carers, including 13,000 young carers.

In addition, The Princess Royal Trust for Carers acts independently in the interests of carers through research and consultation to influence national, regional and local policy and practice in partnership with other national organisations.

LINKS

-  www.disabledparentsnetwork.org.uk
-  www.carers.org
-  www.youngcarers.net

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