



The  
Children's  
Society

# Young carers, parents and their families: **key principles of practice**

Supportive practice guidance for those who work directly with, or commission services for, young carers and their families

Jenny Frank and Julie McLarnon

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or commission services for, young carers and their families

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**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, some of whom may be 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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**Young carers are children first and should be free to develop emotionally and physically and to take full advantage of opportunities for educational achievement and life success.**

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# Foreword

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For most young people, dealing with friendships with peers and the trials of growing up can be stressful enough. But for some, these worries may be just the tip of the iceberg. Young carers face additional challenges in their home life that can be real obstacles to doing well at school, developing friendships or exploring their interests – things that should be part of everyone’s childhood.

When the Government published *Every Child Matters*, we said we would make sure every child got the chances they needed to succeed in life, whatever their background; and that to do this, we would make sure those who work with children – teachers, and professionals in health and social care – could work together to support the needs of children and families. That includes the needs of young carers.

On 10 June 2008, we launched the new national Carers Strategy, “Carers at the heart of 21st century families and communities”. This marks a further, major step forward in our work to ensure young carers have the opportunities to learn and achieve as other young people do. Protecting children from falling into excessive and inappropriate caring roles is the strategy’s overriding goal in relation to young carers. Too often young carers take on caring roles that are too much for them, which can harm their education and welfare. We need to do more to prevent this. We will improve support to families with young carers so that they are better protected from having to take on inappropriate or excessive caring roles. We also want to make sure that schools and other front line services can better identify young carers and know how to support them. The new measures, worth over £6m, will bring to nearly £10 million our total investment in support for young carers and their families over the next three years to 2011.

This new guidance from The Children’s Society is specifically designed to help practitioners working with young carers and their families to provide better support for them. It is written by professionals, for professionals with input from young carers and their families and helps establish clear expectations

for how those working with young carers can help them and their families access the support they need.

It is only right that young carers should get the same opportunities for a fulfilling childhood and as good an education as their peers. Every child, whatever their background or circumstances, should have the chance to succeed in life. We therefore wholeheartedly welcome this contribution from The Children's Society as a further, valuable resource for all those who work with young carers and their families.



**IVAN LEWIS**

Parliamentary Under Secretary of State  
for Care Services



**KEVIN BRENNAN**

Parliamentary Under Secretary of State  
for Children, Young People and Families

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# Introduction

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Key principles are a set of values that underpin what people think, say or do. The content of this document takes account of legislation and guidance, but importantly it reflects consultations with young carers and their families and knowledge gained over a number of years through the work of The Children's Society's Young Carers Initiative.

These Key Principles have been put together to promote a common understanding of the set of values that should underpin all support for young carers and their families and to inform policy-makers and practitioners when developing and providing services. The Principles should give clarity, direction and purpose to professional practice and be used to help measure success and build further improvements in the delivery of services and support.

A supportive online resource, the **Whole Family Pathway**, designed to be used alongside this publication, is available at [www.youngcarer.com](http://www.youngcarer.com)

These Key Principles are endorsed by:  
The Disabled Parent's Network  
The Princess Royal Trust for Carers

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# How to use these Key Principles

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In recent years there have been a number of national policy initiatives of relevance to young carers and their families. Legislation has been put in place and guidance published to support agencies in responding to these recommendations in ways that are sensitive to the needs of young carers and their families. These Key Principles of Practice are intended to be used alongside current legislation and guidance, a summary of which is included on pages 14-42.

Using the Key Principles of Practice will help to ensure the best use of resources to deliver support to the whole family.

Threading the Key Principles throughout practice will also:

- influence change and clarify lines of accountability
- support inter-agency joint practice and vital joint working between adults' services and children's services.
- encourage young carers and families to come forward and self-refer at an early stage
- make the identification and assessment of any needs holistic and more effective
- support disabled parents' entitlements to assessments and services, including any parenting support needs
- work towards ensuring that young carers and their families receive the same high standards of support and services wherever they are in the country
- work towards ensuring that children do not take on inappropriate roles and responsibilities.

Further examples of good practice may be found in *Making it Work* (Frank, 2002).

*“No care package should depend on the inappropriate caring role of a child.”*

(Carers (Equal Opportunities) Act 2004 Practice Guidance)

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# PART 1

## Background and context

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### The impact of being a young carer

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.

Many young carers have problems at school, including poor educational performance and difficulty fitting in with their peers. Such problems may be a consequence of poor attendance at school and the pressure and stress caused by caring responsibilities. Between 13 per cent of those of primary school age and 27 per cent of those of secondary school age are experiencing some problems at school (Dearden and Becker, 2004). In addition, when families include someone with a disability the family income is likely to be lower than average, this may affect the young person's opportunities for further education.

*(Source: Implementing the Carers (Equal Opportunities) Act 2004 Practice Guidance)*

### Identifying a young carer

The legal definition of young carers, as stated in the **Carers (Recognition and Services) Act 1995**, is: “*Children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis*”.

However, it is important that not only the extent and nature of the caring that a child or young person may be providing is recognised, but the actual or potential impact this has on the young carer.

While most children and young people help out parents to some degree, many take on caring responsibilities for family members that are inappropriate for a child of any age to undertake. They may be caring for siblings, grandparents and parents. They are often responsible from a young age for tasks such as intimate or personal care, helping someone to get around, household tasks such as shopping, cooking, cleaning and paying bills, giving emotional support and helping to look after younger siblings.

**These Key Principles of Practice are based on the following premise.**

**A young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her own emotional or physical well-being or educational achievement and life chances.**

A large body of evidence from research and practice compiled by Becker, Aldridge, Dearden, Frank, Bibby, Shah and Hutton has highlighted that caring has a high emotional element for the children. Many young carers have described the worry and anxiety that they experience when someone close to them is ill or disabled.

Many lists of how to identify a carer have been compiled over the years. The question that needs to be asked is at what point, in what circumstances and by whom should children and young people be classed as 'young carers'?

It is important to differentiate between a 'normal' level of caring within a family and a level of 'inappropriate physical or emotional caring' that affects or is likely to affect a child's own personal, social and educational development. Moreover, some children see themselves as young carers, while others do not. It is vital to listen to their points of view about definition and perceptions and to understand the issues and factors that may have led them to becoming a young carer. Even when all the practical and physical care needs of the person who has a long-term illness or disability are being met, children still say that they care emotionally and worry about the person (Frank, 2002).

### Using definitions

This document 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 is recognised that not all parents included in our definition would define themselves as disabled people.

The definition of 'parents' includes prospective parents, biological parents, grandparents, same-sex couples, those who raise, adopt or foster children and step-parents.

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### Social model of disability

*"The social model of disability has been created by disabled people and is a way of seeing which is more accurate and therefore more useful and empowering. It sees us as people who are disabled by all the barriers that exist in society: barriers of attitudes, of economies, of the way things are organised and of the built environment. The model also sees a solution to disablement - society as a whole taking responsibility for removing all the barriers that currently restrict our lives."*

(Department of Health, 1996)

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*"It's not just the caring that affects you... What really gets you is the worry of it all."*

(former young carer quoted in Frank, 2002)

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## Effective assessments

Giving inappropriate levels of care can affect a child's physical and emotional well-being and personal, social and educational development. This will vary according to a child's age, level and impact of caring, and therefore only a good assessment can identify when intervention and additional support for the child is needed. Timely 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.

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Families dealing with illness or disability will have many different and perhaps conflicting emotions. For the parent there may be a reluctance to accept the nature of illness and the associated care needs and to seek help. For the child the fact that they may 'not know any different', coupled with feelings of loyalty and love, may conflict with the need to ask for help. All these may compound to prevent many families seeking timely early intervention.

Identification of young carers can be problematic. Many children live with family members with stigmatised conditions such as mental illness or drug and alcohol problems. In many cases, families fear what professional intervention may lead to if they are identified. Some families may also have concerns about the stigmatisation of being assessed under children's legislation. (**Carers (Equal Opportunities) Act 2004**)

*"Resources are important and necessary to provide support to our families and us. However, even with 24-hour care, young carers would still exist – we are part of a family and have feelings that need to be recognised – we have all sorts of feelings."*

(young carer)

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## Adults' services and identification

"Adults' services, in addition to supporting disabled parents, have a key role in identifying young carers, as they will often be the first point of contact. At the point of assessing the cared-for person, adults' services must ask whether the person they are assessing has children and, if they do, what impact they feel their disability has on them.

## Other family members

Some children live with disabled siblings or grandparents and take on some caring responsibilities to support their parents who are the main carers. In the absence of their own parents, other children may live with grandparents who have care needs."

(Carers (Equal Opportunities) Act 2004 Practice Guidance)

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### Think Family

Good children's services are critical, but adults' services also have a crucial role to play in determining children's achievements and future life chances.

(Cabinet Office, 2008)

## Why do children take caring roles within the family?

Research and practice have shown that children take on caring roles for a large number of reasons (Aldridge and Becker, 1993). Some choose to take on the task voluntarily; others are informally nominated as a carer; and in some families it is expected, even demanded. The majority, however, just grow into the role.

Some of the issues and factors that can lead to a child undertaking inappropriate levels of care are: the number of other adults present and able to assist with care; the type, level and frequency of care needs required; and, significantly, the lack of proper assessment processes and provision of effective and flexible services to the family home and person who has care needs. Additionally, children and families may not know where to seek help because of a lack of local information. Some families do not believe they need help or recognise that inappropriate care is taking place. (Frank, 2002)

It must be remembered, however, that not all children in families where a member has a disability will necessarily be young carers.

Young carers and the needs of the person for whom they are caring may only be identified when there is a crisis. Even then, the extent of the child's caring role and the impact that it has on their own development may not be recognised quickly or fully assessed, with the result that families may not receive the services they require soon enough. Additionally, parents whose personal care needs are assessed do not always have their parenting needs taken into consideration.

### 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 parent carers. Emotional support to a sibling is also a feature of caring for many.

#### Think Family

Adult services need to consider the parental roles and responsibilities of their clients.

(Cabinet Office, 2008)

*“Provide sign language courses for me and my family to learn a lot more sign language to communicate better with my sister.”*

(young carer)

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## Positive aspects of caring

The experience of being a young carer can have some positive aspects. Young carers can be highly self-motivated multi-taskers, coping with and achieving at school while undertaking a caring role. Many transfer their caring skills into career and job choices (Frank, Tatum and Tucker, 1999) having developed many key skills and competencies that were needed for their families to function. Such skills include effective communication and management capabilities, often coupled with a mature outlook – although there is currently no way of accrediting these skills so that colleges or employers recognise them. (Dearden and Becker, 2000)

However, it is important that such recognition does not inadvertently encourage the continuation of inappropriate care nor that caring becomes a cause for celebration and not action. It is also important that careers advisors do not assume that the care profession should be the only career path for young carers but that they help them to explore all options. It is also important that young carers' abilities to cope and achieve should not be allowed to mask their need for support. (Dearden and Becker, 2000)

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## Inclusive practice

While the combination of issues and factors that lead to a child undertaking inappropriate levels of care is unique to each family, it is important that special consideration is given to specific groups to ensure inclusive working practice, especially when undertaking an assessment of needs.

For example:

- black and minority ethnic groups
- refugees and asylum-seekers
- parents dependent on drugs or alcohol
- parents with mental ill-health
- parents with HIV/AIDS
- families in rural areas
- very young carers.

*“We are often scared that a stranger is looking after the person we care for, but if a relationship was built up that would be better.”*

(young carer)

## **Young carers from black communities and other ethnic groups, including Gypsy, Roma and Traveller communities and those for whom English is an additional language**

In addition to sharing the specific experiences of all young carers, those from black communities and other ethnic groups face other issues:

- Some families may be less likely to contact social services departments for fear that their children will be taken away.
- Children from some of these groups are more likely to be excluded from school.
- Children from some of these groups are often expected to take responsibility for interpreting for the person they are caring for, regardless of whether or not they understand the issue or it is appropriate to their age.

(Source: Department of Health, 1999)

Additionally, children from these groups may:

- be less able to access information about services
- be less able to articulate needs
- experience racial discrimination as well as discrimination due to disability or illness
- face cultural interpretations of illness and disability, which may manifest as discrimination or an unwillingness to understand or accept disability.

Families in these communities may feel uncertain about support from formal sources because of cultural expectations of their role and a perception of their duty to look after their elders.

## **Refugees and asylum-seekers**

It is well documented that many refugees and asylum-seekers arrive in trauma or experiencing mental distress, illness or disability. However, the health problems of asylum-seekers are not always specific to their refugee status and may be shared with other deprived or excluded groups. Physical and mental health problems can include diseases linked to poverty and overcrowding, including communicable diseases, psychological and social health problems, and stress-related physical health problems. Refugees and asylum-seekers

may also have problems with memory, concentration and disorientation, which could hinder learning, including learning a new language. (British Medical Association, 2002)

It is not good practice to expect children to interpret for family members, particularly where there is an illness involved. Service providers must ensure that any need for professional interpreters is properly addressed. (Department of Health, 1999)

## Parents dependent on drugs or alcohol

In England, between two and three per cent of children and young people live with a parent or carer who misuses drugs. Even more live with someone who misuses alcohol. In a school which has 1,000 pupils, therefore, about 20–30 pupils will have a parent who misuses drugs and there will be even more whose parents misuse alcohol. (Advisory Council on the Misuse of Drugs, 2003)

It is very important to listen to the perspective of the child and how the impact of their parent's dependency is affecting their well-being and development. Their caring responsibilities may be difficult to identify and quantify. But in addition to practical tasks such as preparing food, household duties and personal care, they may include ensuring the safety of their parent, looking after younger siblings and giving emotional support. Like all young carers, the children may also experience feelings of anxiety. Many of these families and children will feel anxious about revealing their problems and taking the first steps to seeking help.

## Parents with 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 parents' behaviour.

### Parental drug misuse

The 2008–2018 *Strategy Drugs: protecting families and communities* has as one of its four strands of work to “prevent harm to children, young people and families affected by drug misuse”. It also aims to improve support to parents with drug problems so that children do not fall into excessive or inappropriate caring roles.

(<http://drugs.homeoffice.gov.uk/publication-search/drug-strategy/drug-strategy-2008-2018>)

### Children caring for parents with mental health problems

The Department of Health identifies 10,000 children who could be at risk of mental health problems due to their caring responsibilities for a parent with mental health problems.

(Department of Health, 1999)

## Parents with HIV / AIDS

Children whose parents have 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 all hide the level of caring that a child is undertaking, particularly at an emotional level.

Equally, in some families the child may not have been told that their family member has AIDS, so they may be caring but not know the true diagnosis.

## Families in rural areas

Families living in rural areas may need extra resources to access services such as transport and there may be a more limited choice of services in sparsely populated areas.

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## Obstacles to using and providing rural social care

### Key messages

- There is considerable variability in the provision of services to people living in rural areas but, overall, they are less likely to receive services comparable with their urban counterparts.
- Rural services cost more to deliver than those in urban areas and a higher burden in the time and cost of access falls upon rural service users.
- The needs of some rural dwellers, especially those from minority ethnic groups, are often neglected.

Efforts to ensure equity, in terms of the standards and levels of service provision through policy initiatives such as 'rural standards' and 'rural proofing', have had mixed success so far.

(Pugh et al, 2007)

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## Very young carers

The 2001 census figures show that there are over 5,000 children aged between five and seven years who are undertaking significant amounts of care. There is little research on this subject, although there is some information regarding the siblings of sick and/or disabled children (Barrell, 2004), the numbers of whom are rising due to advances in medical technology and nursing care.

There are no figures for the numbers of children aged younger than five who are carrying out caring roles. But assuming that young carers do not simply appear at the age of five, it is important to consider how to support very young carers effectively through age-appropriate assessment techniques and a thorough understanding of child development.

## Supporting the person in need of care and the whole-family approach

For services to provide effective support for young carers and their families, it is vital that all members of staff working with them begin with an inclusive, wide-ranging and holistic approach that considers the needs of:

- the adult or child in need of personal care
- the child who may be caring
- the family.

The concepts that underpin the whole-family approach are not new. This document explores the legislation and guidance that, if used effectively, can make a meaningful difference to the lives of these children and their families.

## Supporting the child who is caring

In an ideal world, of course, there would not be any children who are caring for family members to such a level that their emotional and physical responsibilities impact on their own development. Local systems of support will vary, but the continuing value of young carers projects or similar direct services made available through local targeted youth support needs to be recognised. However, the reality is that it is going to take considerable time and resources to meet effectively and consistently the care needs of all parents who are ill or disabled, while many parents with substance misuse or mental health problems will continue to be hidden from services.

In the meantime, children **do** find themselves in inappropriate caring roles. Many find their own well-being and development affected and will benefit from various degrees of support. The continuing value of Young Carers Projects and similar direct services should be recognised, valued and adequately funded for sustainability.

*“The caring task is something that ‘never stops’.”*

(young carer)

## Families where a parent is ill or disabled

Both the personal care needs and the parenting needs of the disabled or ill parent should always be a starting point when a young carer is identified. This will ensure that children are not being supported to carry out inappropriate tasks, but that parents receive the practical, emotional and financial support that will increase their capacity to parent.

The personal care and parenting support needs of the ill or disabled person should be sufficiently met to prevent inappropriate levels of caring by any child and that care becoming the unstated part of an individual care plan. To achieve this requires the effective use of whole-family assessment processes, **whichever** agency makes or receives a referral.

At present, parents are often unable to access support for their parenting needs until lack of support leads to their children experiencing difficulties and being assessed as being *'in need'* under the **Children Act 1989**. This is a sign that support for that parent and their family has already failed, often as a result of a lack of co-ordination between services for adults and services for children. Parents should be able to access support that prevents their children experiencing difficulties that lead to them being labelled as *'in need'* (The Children's Society et al, 2004). Early support, delivered in a non-judgemental and empowering way, can make all the difference to a parent's ability to look after their children (Morris, 2003).

Councils should ensure that parenting support needs are included in all eligibility criteria levels from 'low' to 'critical', as stated in the Department of Health's guidance on eligibility criteria for adult social care, **Fair Access to Care Services**.

### Using definitions

This document 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 is recognised that not all parents included in our definition would define themselves as disabled people.

The definition of 'parents' includes prospective parents, biological parents, grandparents, same-sex couples, those who raise, adopt or foster children and step-parents.

*"I did not want my son to do my personal care needs. Social Services do not seem to tie the two together, that I am disabled and that I have a son who has all the responsibility for me. It would have been useful if they had asked to speak to me and my son together – and in that way they might have realised how much he does for me."*

(disabled parent)

## Families who have disabled or ill children

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.

## The statistics – how many young carers are there?

2001 Census figures state that in England there are approximately 139,000 children under the age of 18 providing unpaid care within their family. However, this may still be an underestimate, as it may well not include many who are 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?'*

### Number of young carers in England, ages and hours spent caring per week

Age	Hours			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)

A Home Office report (Advisory Council on the Misuse of Drugs, 2003) estimates that in the UK there are between 250,000 and 350,000 children of problem drug-users. Alcohol Concern estimate that there are up to 1.3 million children in the UK affected by a parental alcohol problem (Prime Minister's Strategy Unit, 2004). These children are not necessarily carers, but many may be taking on responsibilities that are disproportionate to their age.

## Young carers in the UK

The third national survey of young carers (Dearden and Becker, 2004) is based on data collated from 87 projects across the UK concerning a total of 6,178 young carers. The authors recorded the following findings:

- 56% of the sample are girls, 44% are boys; the average age is 12.
- 84% of the sample is white; the largest minority group is African Caribbean.
- 56% of young carers are living in lone-parent families.
- People with care needs have a range of illnesses or physical or mental health problems. Half of all conditions are of a physical health nature; 29% are mental health problems; 17% are learning difficulties; and 3% are sensory impairments.
- The majority of people with care needs are mothers. This is especially true in lone-parent families, where mothers account for 70% of people needing care. In two-parent families almost half (46%) of people receiving care are siblings.
- Only 4% of adults with care needs are in employment (where data available).
- Where there is at least one adult in the home (in addition to any adult with care needs), only slightly more than half of these other adults are also in employment (where data available).
- Two-thirds of the young carers provide domestic help in the home; 48% provide general and nursing-type care; 82% provide emotional support and supervision; 18% provide intimate personal care; and 11% also provide child care. The recognised incidence of emotional support has increased dramatically since 1997.

*“Remember we will still be caring after we are 18. Who will help us then?”*

(young carer)

- Intimate care is most commonly provided where the person with care needs has a physical health problem or disability. Emotional support is far more common where the person has mental health problems.
- One in ten young carers is caring for more than one person.
- Overall, girls are more involved in all types of caring tasks, especially as they get older.
- Half the young carers are caring for ten hours or less per week; one-third for 11–20 hours per week; and 16% for over 20 hours per week. Some (2%) are caring for more than 50 hours each week.
- The overall incidence of missed school and educational difficulties has reduced, decreasing between 1995 and 1997 and again between 1997 and 2003. However, 27% of all young carers of secondary school-age are experiencing some problems, and the equivalent proportion of young carers of primary school age is 13%.
- Four in ten children caring for someone who misuses drugs or alcohol have educational difficulties.
- Caring can be a very long-term commitment for many children and can start at an early age. One-third (36%) of young carers have been caring for two years or less; 44% for three to five years; 18% for six to ten years and 3% for over ten years.

*“Leaving my mother. That’s the main thing. I just don’t see how me and my sister could ever do that. I know my sister doesn’t want to leave home at all.”*

(young carer)

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## PART 2

# Summary of legislation, guidance and other key publications

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**An index of the legislation and guidance in this section can be found on page 80.**

The practice guidance to the **Carers (Equal Opportunities) Act 2004** (Social Care Institute for Excellence, 2005) states that local authorities should have “*a protocol, shared between adults’ and children’s services, for identifying and assessing young carers*”. The challenge, however, is to ensure that such a protocol is put into action in order to deliver a seamless service, which also demonstrates shared accountability.

This section provides a summary of the legislation and guidance that may be used by managers and practitioners to support young carers and their families. It includes both children’s legislation and legislation concerning adult health and social care. The web links may be used if more detailed information is required.

## Children’s legislation and guidance

### The Children Act 2004 and guidance

<http://www.everychildmatters.gov.uk/strategy/guidance/>

The Children Act 2004 provides the legal underpinning for **Every Child Matters: Change for Children** – the government programme aimed at improving children’s lives and integrating children’s services. The programme covers the universal services which every child accesses, such as education, and more targeted or specialist services for those with additional or special needs.

The overall aim is to improve the outcomes for children and young people by encouraging partnership arrangements (Children's Trusts) which bring together, under Section 10 of the Act (the 'duty to co-operate'), key agencies that deliver services for children young people and their families.

Children's Trusts represent a new way of working which puts the child at the centre of planning and delivery of services. They support integrated planning, commissioning and delivery of services, multi-disciplinary working and clear lines of accountability. This means that children and young people should experience more integrated and responsive services and specialist support, resulting in earlier and more effective support for children and families.

Statutory guidance on the inter-agency 'duty to co-operate' is available on the Every Child Matters website at:  
<http://www.everychildmatters.gov.uk/>

Local authorities are also required, under Section 17 of the Act, to produce a single overarching strategic plan for all services affecting children and young people. The Children and Young People's Plan is prepared by each local authority in close co-operation with its partners in the children's trust and should set out a local vision for improving the well-being of children and young people and detail the priorities and actions for delivering that vision. The local authority must consult widely on the plan and include children, young people and their parents or carers, the voluntary and community sector, as well as the key partners within the Children's Trust.

The legislation is enabling rather than prescriptive and provides local authorities with a considerable amount of flexibility in the way they implement its provisions. A series of documents have been published which provide guidance under the Act, to support local authorities and their partners in implementing their new statutory duties.

Details about the implementation of the Act and the wider reform programme are available in *Every Child Matters: Change for Children* (HM Government, 2004).

## Every Child Matters: Change for Children

<http://www.everychildmatters.gov.uk/>

*Every Child Matters* (HM Government, 2003) sets out five outcomes that children and young people said were important to them:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution to society
- achieve economic well-being.

NB: The outcomes of the Key Principles for Practice presented in this document, which are listed at the end of each Principle, map across to the *Every Child Matters* outcomes.

Young carers and their families were identified as a group that would particularly benefit from targeted, sensitive help. Chapter three (Supporting Families and Carers) describes the government plans to make support services more accessible: *“through a wider range of universal services, provided without stigma, and easy to access, targeted services for specific groups, and specialist support for individual children and their families”*.

*Every Child Matters: Change for Children* (HM Government, 2004) sets out a national programme designed to help ensure that **every** child age 0-19 years – whatever their background or their circumstances – has the support they need to achieve the five outcomes.

It sets out how local service providers should be integrated in new ways, to support families in helping children and young people achieve these outcomes. Services will have a greater focus on early intervention. Frontline staff will increasingly work together in multi-disciplinary teams, sharing and accessing information about a child’s circumstances so that problems can be identified as they arise. Lead professionals will help ensure the child receives the tailored support they need. Locally, there will be a sharper focus on accountability for the performance of children’s services. Children, young people and families themselves should have far more say in the design and delivery of the services they use.

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## Parental drug misuse

*Working Together to Safeguard Children (DfES, 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
  - inter-agency 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 Drug Action Teams (DATs) or Drug and Alcohol Action Teams (DAATs) and other agencies that can assist in the assessment and outcomes.
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## The Children's Plan

[http://www.dcsf.gov.uk/publications/childrensplan/downloads/The\\_Childrens\\_Plan.pdf](http://www.dcsf.gov.uk/publications/childrensplan/downloads/The_Childrens_Plan.pdf)

The Children's Plan, launched in 2007 by the Department for Children, Schools and Families (DCSF), sets out plans for the next ten years under each of the DCSF's strategic objectives. It presents the Government's vision for supporting families to get the basics right for all children and young people so that their lives are free from poverty and they enjoy good physical health and mental well-being. Five principles underpin the Children's Plan:

- Government does not bring up children – parents do. So government needs to do more to back parents and families.
- All children have the potential to succeed and should go as far as their talents can take them.
- Children and young people need to enjoy their childhood as well as grow up prepared for adult life.
- Services need to be shaped by and responsive to children, young people and families, not designed around professional boundaries.
- It is always better to prevent failure than tackle a crisis later.

### **Staying Safe Action Plan 2008**

**Staying safe is a fundamental part of the Children's Plan: children cannot enjoy their childhoods or achieve their full potential unless they are safe. The Staying Safe Action Plan is linked to the Children's Plan:**

[http://www.everychildmatters.gov.uk/\\_files/E311A3DE50297A05E31F401F17DC67EB.pdf](http://www.everychildmatters.gov.uk/_files/E311A3DE50297A05E31F401F17DC67EB.pdf)

The Children's Plan states that, for young carers, services should adopt a whole-family approach. This means that children's and adults' 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.

## Children Act 1989

[http://www.opsi.gov.uk/acts/acts1989/Ukpga\\_19890041\\_en\\_1.htm](http://www.opsi.gov.uk/acts/acts1989/Ukpga_19890041_en_1.htm)

If a child does not have the opportunity or is unable to achieve or maintain a *"reasonable standard of health or development"*, then they are regarded as being *"in need"*. This in turn means they are eligible for a range of support services.

Under Section 17 of the Children Act 1989, a young carer may be regarded as a child in need if *"he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority under this Part; his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or he is disabled"*.

The *"reasonable standard of health or development"* is not clearly defined.

However, the Act does not assume that young carers suffer *"significant harm"* (in the sense of Section 31 and elsewhere in the text) simply because they are performing a caring role. It also **does** state that children are best cared for within their own family and that any intervention taken must be beneficial to the child and take account of the child's wishes. This is important, given the frequently reported concerns of both young carers and their parents that the involvement of social services may lead to the child being removed from their family.

*"A young carer may be a child in need under the Children Act. The key issue is whether the child's welfare or development might suffer if support is not provided to the child or family."*

(Department of Health, January 2000)

# Assessment

## Common Assessment Framework

<http://www.everychildmatters.gov.uk/deliveringservices/caf/>

The Common Assessment Framework (CAF) for children and young people is also a key part of the strategy to shift the focus from dealing with the consequences of difficulties in children's lives to **preventing** things from going wrong in the first place. It is a nationally standardised approach to conducting an assessment of the additional needs of a child or young person and deciding how those needs should be met.

The CAF is intended to provide a simple, non-bureaucratic process for a holistic assessment of a child's additional needs, taking account of the individual child, their family and their community. It has been developed for use by practitioners in all agencies so that they can communicate and work more effectively together.

It will:

- promote earlier intervention where additional needs are identified, reducing the demand for specialist services
- avoid duplication and reduce the scale of specialist assessment processes that children and young people need to undergo
- improve the quality and consistency of referrals between agencies by making them more evidence-based
- promote a shared understanding by practitioners through a common language about the needs of children
- promote the appropriate sharing of information, saving time for practitioners.

The CAF is particularly suitable for use in universal services (health and education), as a means of identifying and tackling problems before they become serious. The use of the CAF should streamline relationships between schools and specialist support services.

The CAF is one of the processes to help local areas to develop Children's Trust arrangements. In April 2006, CAF guidance was issued alongside guidance on the lead professional role and information sharing, at [www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk).

### Delivering CAF

**Any trained practitioner working with the child or their family can undertake the CAF. With training and support, adults' services such as housing and the police could become more confident in identifying when a child may have additional needs, and in approaching others to undertake a CAF where appropriate.**

(Cabinet Office, 2008)

Within schools, staff will need to be familiar with the CAF, which will support a school's own ability to identify and deal with a child's additional needs at an early stage. Staff will need to be aware of local arrangements for checking whether a CAF already exists and, if it does, how to contact the relevant practitioner. When the Contact Point has been introduced, it will cut down time spent on wasted unnecessary referrals, or trying to find out who else is working with a particular child. Designated key staff (rather than all teachers) will form part of a wider team with other professionals to address individual children's additional or complex needs.

If a common assessment suggests that a child has needs that require input from more than one service, it is recommended that one practitioner acts in the role of lead professional to:

- provide a single point of contact for children, young people and families to trust, and support them in making choices and in navigating their way through the system
- co-ordinate the delivery of the actions agreed by the practitioners involved
- ensure that children and families get appropriate interventions when they are needed and that these are well planned, regularly reviewed and effectively delivered
- reduce overlap and inconsistency in the services provided.

The CAF will help practitioners undertake assessments in a more consistent way. In many cases, it will simply formalise current practice. It is expected that, in any agency, practitioners with the right skills, knowledge and confidence will be able to undertake a common assessment. Where the assessment indicates that the child has needs requiring specialist assessment and intervention, the common assessment information will feed into the specialist assessment process.

*“If you are on your own and no one else is there to help and you can't get out of house, it makes you lonely and depressed. It's very hard when there is no one to talk to.”*

(young carer)

## Framework for the Assessment of Children in Need and their Families Guidance

[http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4003256&chk=Fss1ka](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4003256&chk=Fss1ka)

This describes a framework for assessing children's and families needs in order to identify "*whether the child being assessed is in need and which services would best meet the needs of this child and their family*". The needs of disabled family members must also be considered in the assessment.

Explicit reference is made to the needs of young carers as follows:

"3.61 A group of children whose needs are increasingly more clearly recognised are young carers, for example those who assume important caring responsibilities for parents and siblings. Some children care for parents who are disabled, physically or mentally ill, others for parents dependent on alcohol or involved in drug misuse. For further information and guidance refer to the *Carers (Recognition and Services) Act 1995: Policy guidance and practice guide* (Department of Health, 1996) and *Young Carers: Making a Start* (Department of Health, 1998).

3.62 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. There may be differences of view between children and parents about appropriate levels of care. Such differences may be out in the open or concealed. The resolution of such tensions will require good quality joint work between adult and children's social services as well as co-operation from schools and health care workers. This work should include direct work with the young carer to understand his or her perspective and opinions. The young person who is a primary carer of his or her parent or sibling may have a good understanding of the family's functioning and needs, which should be incorporated into the assessment.

3.63 Young carers can receive help from both local and health authorities. Where a child is providing a substantial amount of care on a regular basis for a parent, the child will be entitled to an assessment of their ability to care under section 1(1) of the **Carers (Recognition and Services) Act 1995** and the local authority must take that assessment into account in deciding what community care services to provide for the parent. Many young carers are not aware that they can ask for such an assessment. In addition, consideration must be given as to whether a young carer is a child in need under the **Children Act 1989**. The central issue is whether a child's welfare or development might suffer if support is not provided to the child or family. As part of the **National Strategy for Carers** (Department of Health, 1999), local authorities should take steps to identify children with additional family burdens. Services should be provided to promote the health and development of young carers while not undermining the parent."

## Carers' legislation and guidance

### The Carers' Strategy 2008 – Carers at the heart of 21st century families and communities

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_085345](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345)

The Carers' Strategy 2008 sets out a ten-year plan for all carers and provides the following definition of a carer:

*"A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems."*

During the consultation process, young carers were particularly concerned about gaps in support around the family and the person they care for and made it clear that better support for their family and the person cared for was the priority. They also said they worry about their own problems – missing out on the opportunities other young people have.

#### The Vision

Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

The Strategy states that:

*Children should not have to take on inappropriate types and levels of caring, which can affect school attendance, emotional and physical well-being and longer-term life opportunities.*

The Strategy sets out short-term and longer-term goals. In the short term it aims to develop:

- more support for schools to help them in their support for young carers
- awareness-raising on caring and the issues it raises across children's settings more generally
- training materials for health professionals
- preventing children from falling into inappropriate caring – action to help build better, more preventative support
- action to ensure better joined-up support around the family
- training for staff in local services on whole-family working.

In the longer term the Strategy will consider what more can be done, on the basis of ongoing pilots and research, to improve protection for young carers.

The Strategy further states that:

*“All these measures together provide a significant new platform for progress and many local services are already innovating and adapting services around whole-family principles. But too many young carers are still shouldering significant responsibilities or undertaking caring of a type which is inappropriate for their age. Too many are reaching projects and accessing support only when problems are well established, and in some cases deeply entrenched. We need further, focused action to help change this.”*

### **A cultural shift**

**Over the next three years to 2011, the Strategy will ensure that support and understanding for young carers and their needs is better embedded within universal and targeted services. However, the overriding objective is to move systems of support towards better prevention. The substantial new investments in support of whole-family working reflect that.**

(Carers' Strategy, Department of Health, 2008)

## **Carers (Equal Opportunities) Act 2004**

<http://www.scie.org.uk/publications/practiceguides/carersguidance/about.asp>

The practice guidance for this Act translates existing knowledge from research and policy into recommendations for practice, with practice-based examples.

It states that, *“There is widespread agreement that children should not be undertaking regular and substantial caring*

*responsibilities or inappropriate personal care tasks” and that “Local authorities have a responsibility to ensure that the person needing care has appropriate services and this should include help with parenting tasks”.*

The guidance also makes the following recommendations:

- No care package should depend on the inappropriate caring role of a child.
- Ensure that there is a multi-agency strategy that addresses the needs of young carers and, where possible, is linked to the Children and Young People’s Plan for the local area.
- Have in place a protocol, shared between adults’ and children’s services, for identifying and assessing young carers.
- Adopt a whole-family perspective, working jointly with statutory services for children and adults, voluntary services, education and (for children of 13 years and older) Connexions.
- Ensure that all assessments of adults include a check to find out if there are children in the family who either take on, or are at risk of taking on, a caring role.
- In line with **Fair Access to Care Services (FACS) guidance**, ensure that adults’ services support disabled people in their parenting role.
- Ensure that the authority has a senior lead on young carers to resolve promptly disputes between adults’ and children’s services.
- If a young carer requests an assessment under the 1995 Act, the local authority must carry out one. As a matter of good practice, however, and in line with **Children Act 1989 guidance**, the **Framework for the Assessment of Children in Need and their Families** – see particularly paragraphs 3.61–3.63 – should be used, as it provides for a more holistic assessment under the Children Act 1989. The policy guidance states that *“the new obligation to consider a young carer’s wish to work or undertake education, training or leisure would still apply,”* regardless of the legislation under which they were assessed.
- Thirty-five per cent of young carers are 16–17 years old. This group has needs that differ from those of younger carers, particularly in light of the requirements of the Children Act 2004 to consider training, employment and leisure needs during Assessment.

### **Exemplar Protocol for Local Authority Adults’ and Children’s Services – Joint assessment and support for young carers and their families**

The practice guidance for the Carers (Equal Opportunities) Act 2004 (SCIE, 2005) states that local authorities should have “a protocol, shared between adults’ and children’s services, for identifying and assessing young carers”. The Children’s Society, The Princess Royal Trust for Carers and The Disabled Parents Network have produced a template to assist local authorities to meet this recommendation. A copy is available at [www.youngcarer.com](http://www.youngcarer.com)

## **Carers (Recognition and Services) Act 1995 Section 1**

[http://www.legislation.hmso.gov.uk/acts/acts1995/  
ukpga\\_19950012\\_en\\_1.htm](http://www.legislation.hmso.gov.uk/acts/acts1995/ukpga_19950012_en_1.htm)

All informal carers, including young carers, are entitled to an assessment of their needs separate from the needs of the person for whom they are caring. This is a duty of local authorities. The assessment must, however, be requested. For this to work, young carers and their families have to be aware of services and be willing to approach them. SSI's practice guide to the **Carers (Recognition and Services) Act 1995** (Department of Health, 1996) contains a whole-family checklist (see below).

## **The Carers and Disabled Children Act 2000**

[http://www.opsi.gov.uk/ACTS/acts2000/  
ukpga\\_20000016\\_en\\_1](http://www.opsi.gov.uk/ACTS/acts2000/ukpga_20000016_en_1)

This Act gives carers aged 16 and over (and caring for someone over 18) an entitlement to an assessment of their needs and ability to continue to provide care (independently of the care receiver) and a right to services and direct payments in lieu of services. (However, young carers under 16 have no right to services or support under this Act.) Policy guidance, practice guidance and a practitioner's guide to carers' assessments are all available to aid the implementation of this legislation.

## **Assessment checklists and guidance**

The following checklists and guidance are intended to assist the planning, design and implementation of a full and thorough young carers' assessment. The responses to the checklist will provide an overview of the current situation and priority needs, as well as ensuring that the process is as inclusive as possible. In some cases the information may already exist, and the task of the assessor may be only to gather assessment information assembled by others and evaluate the information for accuracy, appropriateness and completeness. It may be necessary for the person making the assessment to develop new questions in order to gather the required information for specific families.

*“Assessments are also important in order to meet the needs of us and our families. When doing an assessment, it is important to understand how the condition or illness can affect the whole family and how families' needs and individuals' needs may differ but also affect each other.”*

(young carer)

*Young Carers: Something to Think About* (Department of Health, 1996), SSI's Practice Guide to the Carers (Recognition of Services) Act 1995 checklist:

- Listen to the child or young person and respect their views.
- Give time and privacy to children who may need this in order to talk about their situation.
- Acknowledge that this is the way the family copes with disability or illness.
- Acknowledge parents' strengths.
- Beware of undermining parenting capacity.
- Consider what is needed to assist the parent in her/his parenting role.
- Consider the needs of the child(ren) arising from caring responsibilities.
- Consider whether the caring responsibilities are restricting the child's ability to benefit from their education.
- Consider whether the child's emotional and social development are being impaired.
- Remember children must be allowed to be children.
- Provide information on the full range of relevant support services, young carers' groups and contact points for further advice or information on specific issues.

In addition, when carrying out an assessment the following guidelines and practice considerations may be helpful (adapted and condensed from: Becker, 2000 and Dearden and Becker, 2000).

#### **Arrangements before the assessment takes place**

- Families should be told formally that an assessment is taking place and should decide with the assessor who will be present.
- Choose a time and venue appropriate to the whole family.
- Consider if an advocate or interpreter is needed so that children and other family members can participate fully.
- Remember to provide any support needed for family members with sensory or speech impairment.
- Offer the children the opportunity to be assessed separately if they wish.

*“Why doesn't someone tell me what is going on with my mum?”*

(young carer)

### Talking to families

- Recognise that families may be fearful of acknowledging children's caring roles.
- Be cautious about making assumptions.
- Equally, ensure parents do not feel judged when disclosing their child's caring responsibilities.
- Acknowledge that families need to cope in different ways and it is often lack of resources, services and sufficient income that result in children needing to provide inappropriate levels of care.

### Carrying out the assessment

- Families should be given information about their entitlements, as well as on the full range of services available.
- Local authorities should emphasise an inclusive rather than exclusive approach to eligibility criteria.
- Practitioners should respond to young carers' needs for emotional support and counselling.
- Families may need specialist help to discuss the financial implications and/or assistance towards receiving services.
- Families should be given written confirmation of the results of their assessment and other relevant information, such as named practitioners for future contact and details of review arrangements.
- Families and young carers should be regularly consulted about the quality and appropriateness of services.
- Remember that early interventions can prevent young caring becoming established. Emphasis should be on preventing children from taking on inappropriate caring responsibilities, and stopping them becoming institutionalised.

*“Mum’s social worker never talks to me. She ignores me. She doesn’t know half of what I do. We need more help so I don’t have to do so much. It’s wrong – she should ask me what I do.”*

(young carer)

## Rights and inclusion

### The United Nations Convention on the Rights of the Child

<http://www.unicef.org/crc>

The UN Convention was ratified by the UK in 1991. The rights of children cover physical and mental health, education and social welfare. The principles underpinning the Convention are concerned with provision, participation and protection.

According to the Convention, no child or young person should suffer discrimination on the grounds of race, sex, religion or disability, either of the children themselves or of their parents. In practice, however, young carers may experience such discrimination in relation to access to services and education. The specific articles of the Convention that support the rights of young carers and their families are highlighted throughout the Key Principles of Practice.

### Department for Children, Schools and Families guidance on behaviour and school attendance

<http://www.teachernet.gov.uk/wholeschool/behaviour>

Advice and guidance from the DCSF to schools and local authorities on managing behaviour and attendance includes guidance on children at particular risk. The section on young carers reads:

1. Young carers care for a relative who has a disability, physical or mental illness or substance misuse problem. Whilst young people should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances, the 2001 Census found almost 150,000 children and young people undertaking caring roles in England and Wales, including nearly 11,000 who cared for more than 50 hours per week. Young carers may be late or absent from school because of their responsibilities. They may appear to be tired, disengaged, isolated from peers or under-achieving. Many report bullying. Many young carers keep their caring role a secret for fear of inappropriate intervention or because of the stigma surrounding some health conditions, addictions and disabilities.

### The UNCRC

The United Nations Convention on the Rights of the Child (UNCRC) Article 2 states that the Convention applies to all children without discrimination of any kind and whatever type of family they come from. It is explicit that this includes the disability of a child's parents or guardian.

Articles 15 and 31 state that all children have a right to relax and play, and to join in a wide range of activities.

2. Schools can help young carers in two ways. Firstly by helping the family, if they are willing, to contact appropriate community care or adults' services to provide more support to the cared-for person, thus reducing the need for the pupil to take on inappropriate caring responsibilities. Secondly, by providing flexible and sensitive support to the young carer when their caring role is particularly stressful or making it hard for them to complete work on time. Again, outside agencies such as youth services, voluntary sector young carers services and, if appropriate, Child and Adolescent Mental Health Services can assist. There is a voluntary sector database of young carers' services at [www.youngcarer.com](http://www.youngcarer.com). Any referrals to, or discussions with, outside agencies must be undertaken sensitively, confidentially, and with the pupil's knowledge, recognising that both the child and their family have a right to privacy and self-determination. Some children may fear being "put into care" if their parents are seen as unable to cope. It is important to be clear that Section 17 of the Children Act 1989 places a duty on local authorities to safeguard and promote the welfare of children in their area, through the provision of services, and where possible, to promote the upbringing of children within their families.
3. In a genuine crisis, a school can approve absence for a child to care for a relative until other arrangements can be made. The school should set a time limit for the absence and set some school work so the pupil does not fall far behind while at home. It may also be appropriate for a pupil whose close relative is in the final stages of terminal illness to take time off school to be with them.
4. Should the pupil's absence be due to their caring for someone with a long term or recurring illness, this may indicate an inadequate level of support from community care/adults' services. The family may welcome efforts to advocate on their behalf for better support arrangements to be in place for future emergencies. If the family is unwilling to discuss their support needs, that must be respected. The school should nevertheless consider and address the pupil's welfare using their usual assessment procedures.

*"Revision classes are after school, so I can't attend. Dad cares in the day and then works evenings, so I take care when I get home. I have no time for friends."*

(young carer)

*"My mum sent a note in to ask if I got detention, please could it be at lunchtime and not after school. It didn't help. I still got after-school detention and just sat worrying about her all the time."*

(young carer)

5. Schools should consider designating a member of staff to have responsibility for young carers. Pupils and parents should be made aware of what to expect if they contact this staff member, for instance through publicising a School Policy on young carers.
6. Further advice is available on the following TeacherNet pages:  
Young Carers: [www.teachernet.gov.uk/teachingandlearning/library/youngcarersandschools/youngcarers](http://www.teachernet.gov.uk/teachingandlearning/library/youngcarersandschools/youngcarers);  
Helping schools to be in tune with young carers  
[www.teachernet.gov.uk/teachingandlearning/library/youngcarersandschools](http://www.teachernet.gov.uk/teachingandlearning/library/youngcarersandschools)

References to young carers are also built into the DCSF's recently revised guidance to schools on bullying, *Safe to Learn: Embedding anti-bullying work in schools* (see in particular annex B). This can be found at: [www.teachernet.gov.uk/wholeschool/behaviour/tacklingbullying/safetolearn](http://www.teachernet.gov.uk/wholeschool/behaviour/tacklingbullying/safetolearn)

### **Education Maintenance Allowance (EMA)**

EMA is a weekly payment of up to £30 per week for eligible learners attending a valid learning programme; EMA is paid directly to the young person and can help with the day-to-day costs of staying in learning.

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

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### **Children missing education**

<http://www.everychildmatters.gov.uk/ete/childrenmissingeducation/> has a section on children missing education which says:

*“In contributing to the agenda outlined above (Every Child Matters), DCSF issued guidance for “identifying and maintaining contact with children missing, or at risk of going missing, from education”. This guidance highlights good practice, which already exists in LEAs, for identifying children missing from education, plus those at risk of going missing, helping them move back into education (or alternative provision) and maintaining contact to prevent them slipping through the net again. This will help ensure all children and young people receive the universal services they are entitled to.”*

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## **The Disability Discrimination Act 1995 (DDA)**

[www.opsi.gov.uk/acts/acts1995/1995050.htm](http://www.opsi.gov.uk/acts/acts1995/1995050.htm)

The Disability Discrimination Act says that it is discrimination when a disabled person is treated less favourably than someone else and no reasonable explanation can be given. People who provide services to the public, including local authorities, must make “*reasonable adjustments*” (whatever steps they can reasonably be expected to take) so that disabled people are able to use services. Service providers are expected to make sure that their services can be used by disabled people, regardless of whether or not disabled people are currently using the service. Since October 2004, these may include physical alterations to premises.

## **Human Rights Act 1998**

<http://www.hmso.gov.uk/acts/acts1998/19980042.htm>

This Act requires that there should be no discrimination on the grounds of disability in access to services, the right to marry or have a family, and that cultural and linguistic differences should be taken into account in the provision and delivery of services.

## **The Data Protection Act 1998**

<http://www.opsi.gov.uk/ACTS/acts1998/19980029.htm>

This gives users of services the right to see what has been written about them in health or social work records. Personal information should not normally be shared with other people without the consent of the person concerned.

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## **Sharing information**

High-quality training and guidance will help to build practitioners’ confidence and inform their judgement on when it is beneficial, appropriate and legal to share information. Guidance on information sharing for practitioners working with children and young people is available through the Every Child Matters website.

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## Health and social care

### National Health Service (NHS) and Community Care Act 1990

[http://www.legislation.hmso.gov.uk/acts/acts1990/Ukpga\\_19900019\\_en\\_1.htm](http://www.legislation.hmso.gov.uk/acts/acts1990/Ukpga_19900019_en_1.htm)

This Act aims to enable people with physical or other needs to live in their own homes. The Act only relates to people aged 18 or over, but the provision of support to a cared-for parent may indirectly benefit young carers.

Local authorities are required by this Act to carry out assessments of the needs of anyone who appears to be in need of community care services. If the person being assessed is disabled then, according to related legislation cited in the Act, their practical needs for “*greater safety, comfort or convenience*” must be assessed.

### National Service Framework for Children, Young People and Maternity Services

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH\\_4094444](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4094444)

This National Framework to ensure personalised, child-centred health and social care services is particularly important for young carers and those in need of care.

- It sets out a ten-year programme for sustained improvement in children’s health and well-being through setting standards for the care of children, young people, and maternity services.
- It forms an integral part of the Every Child Matters: Change for Children Programme that will, as it is implemented by Primary Care Teams, local authorities and other partners, contribute to the achievement of improved outcomes for children, young people and pregnant women.

The Framework uses the term ‘*children in special circumstances*’ to cover “*a variety of groups of children whose particular circumstances will often lead to them achieving poorer outcomes*”. (Department of Health 6.2 Getting the Right Start:

National Service Framework For Children. Emerging Findings. April 2003)

Additionally, Part 1 Standard 2 of the National Service Framework states that, *“Parents with specific needs such as relationship conflict, mental health problems, addiction to drugs or alcohol, teenage parents or parents of disabled children, have their needs identified early and are provided with effective multi-agency support.”*

(Additional guidance for children caring in families where there is parental ill-health is included in the section on the **National Services Framework for Mental Health** below.)

### **Disabled Persons (Services, Consultation and Representation) Act 1986**

[http://www.opsi.gov.uk/si/si1988/Uksi\\_19880094\\_en\\_1.htm](http://www.opsi.gov.uk/si/si1988/Uksi_19880094_en_1.htm)

Section 8 states: *“Where a disabled person is living at home and receiving a substantial amount of care on a regular basis from another person (who is not a person employed to provide such care by any body in the exercise of its functions under any enactment); and it falls to a Local Authority to decide whether the disabled person’s needs call for the provision by them of any services for him under any of the welfare enactments, the Local Authority shall, in deciding that question, have regard to the ability of that other person to continue to provide such care on a regular basis.”*

### **Chronically Sick and Disabled Persons Act 1970 Section 2**

[http://www.dh.gov.uk/en/PublicationsAndStatistics/LettersAndCirculars/SelectedDiscontinuedSeries/DH\\_4017592](http://www.dh.gov.uk/en/PublicationsAndStatistics/LettersAndCirculars/SelectedDiscontinuedSeries/DH_4017592)

This places a duty on local authorities to assess the individual needs of everyone who falls within Section 29 of the National Assistance Act 1948 in order to meet the needs of ‘disabled people’. These include: provision of practical assistance in the home; provision of recreational facilities outside the home or assistance to take advantage of educational facilities; provision of assistance with works for adaptation in the home; provision of meals.

## National Service Framework for Mental Health 1999

[http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4009598&chk=jmAMLk](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4009598&chk=jmAMLk)

The National Service Framework (NSF) for Mental Health was launched in 1999 and is a comprehensive statement on how mental health services will be planned, delivered and monitored until 2009. The NSF lists seven standards that set targets for the mental health care of adults aged up to 65. These standards span five areas:

- health promotion
- reduction of stigma and exclusion from primary care and access to specialist services
- needs of those with severe and enduring mental illness
- carers' needs
- preventing suicide.

Standard 6 outlines the roles and responsibilities of social services, GPs, primary care teams and others with regard to assessing and meeting the needs of carers, including those of young carers.

## Fair Access to Care Services Practice Guidance

[http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4009653&chk=nadbwl](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4009653&chk=nadbwl)

The framework of Fair Access to Care Services is based on what individuals need in order to ensure their independence and includes four eligibility bands: critical, substantial, moderate and low. When placing individuals in these bands, the guidance stresses that councils should identify not only immediate needs but also needs that would worsen for the lack of timely help.

The guidance emphasises that reviews of individual service users' circumstances should be carried out by appropriate council professionals on a regular and routine basis. It also states that, *"it will be important for children and family teams to have agreed policies and protocols with adult teams on how to respond to the needs of families where the parent is disabled"*. (Department of Health, 2002, p.10)

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## Personalised Adult Social Care System

*Putting People First* (HM Government, 2007) puts forward a shared vision and commitment to the transformation of adult social care. Some key elements include a personalised Adult Social Care System, which will have: *“Agreed and shared outcomes which should ensure people, irrespective of illness or disability, are supported to:*

- *live independently;*
  - *stay healthy and recover quickly from illness;*
  - *exercise maximum control over their own life and where appropriate the lives of their family members*
  - *sustain a family unit which avoids children being required to take on inappropriate caring roles*
  - *participate as active and equal citizens, both economically and socially.”*
- 

*“I would like an assessment for each person in need in our family and for all professionals to get together and talk about us as a family, rather than as separate individuals.”*

(disabled parent)

## The Direct Payments Guidance (Department of Health, 2002)

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4096246](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4096246)

Original practice guidance was published on 2 August 2002. It was updated on 6 March 2003 to assist councils with their final preparations for implementation of the Community Care (Direct Payments) Act 1989.

This guidance aims *“to assist local councils in making direct payments”*. It replaces the passages on direct payments in the *Carers and People with Parental Responsibility for Disabled Children practice and policy guidance*.

The purpose of direct payments is to give recipients control over their own lives by giving them an alternative to social care services provided by a local council. A direct payment gives the person flexibility to look beyond ‘off-the-peg’ service solutions for certain housing, employment, education and leisure activities as well as for personal assistance to meet their assessed needs. This will help increase their opportunities for independence, social inclusion and enhanced self-esteem. Direct payment schemes can facilitate this by building links with local health, housing, education, learning and skills councils and other agencies. Guidance on implementing direct payments states that, *“Councils should*

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*ensure that needs assessments for disabled adults include parenting responsibilities” (Department of Health, 2003)*

The extension of direct payments in lieu of services provided under Section 17 of the **Children Act 1989** (as amended by the **Health and Social Care Act 2001, Section 58**) is an important mechanism for adults’ and children’s services to work together (see below). As the direct payments guidance points out, a *“holistic family assessment, taking account of the needs and views of children and parents”* is already required under Section 7 guidance relating to children (Department of Health et al, 2000, para. 3.32)

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### **Independent living**

*“Independent living is the concept of the empowerment of disabled people and their ability to control their own lives. It is not the name of a particular service or provision but the objective of services and provisions. The ability of an individual to make decisions about their own life gives that individual the freedom to participate fully in the community. This freedom has been, and will continue to be, the essence of independent living.”*

(National Centre for Independent Living)

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*“For five years my daughter did all the housework, took care of my personal needs including going to the toilet and pulling my wheelchair up a flight of stairs. I now have direct payments and I feel able to fulfil my role as a parent. Kelly is now going to school and we both have a life.”*

(disabled parent)

### **Health and Social Care Act 2001 (section 58) amending for Children Act 1989, section 17 re: Direct payments in respect of children**

<http://www.opsi.gov.uk/acts/acts2001/10015—g.htm>

*“For section 17A of the Children Act 1989 (c. 41) there shall be substituted:*

*(1) The Secretary of State may by regulations make provision for and in connection with requiring or authorising the responsible authority in the case of a person of a prescribed description who falls within subsection (2) to make, with that person’s consent, such payments to him as they may determine in accordance with the regulations in respect of his securing the provision of the service mentioned in that subsection.*

*(2) A person falls within this subsection if he is*

- *a person with parental responsibility for a disabled child,*
- *a disabled person with parental responsibility for a child,*  
*or*
- *a disabled child aged 16 or 17.”*

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## Supporting disabled parents and parents with additional support needs

This knowledge review is about parents with physical and/or sensory impairments, learning difficulties, mental health problems, long-term illnesses such as HIV/AIDS, and drug or alcohol problems. Its main focus is on social care, but integral to this are the relationships between social care and health, housing and education.

The knowledge review looks at social care in both the statutory and non-statutory sectors. It pulls together a comprehensive review of the literature, and reports on a diverse range of good practice, that draws upon the experiences of disabled parents. It is predominantly concerned with how policies and practice address the needs of parents, and progress in overcoming barriers. While the needs, experiences and rights of children are important, they are not the central focus of this literature review.

(Morris and Wates, 2006)

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## A Jigsaw of Services: Inspection of services to support disabled adults in their parenting role

[http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsInspectionReports/PublicationsInspectionReportsArticle/fs/en?CONTENT\\_ID=4005103&chk=hgrdpJ](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsInspectionReports/PublicationsInspectionReportsArticle/fs/en?CONTENT_ID=4005103&chk=hgrdpJ)

This document outlines key principles for improving services to disabled parents:

- a recognition of the rights of disabled people to be supported in fulfilling their roles and responsibilities as parents
- a knowledge of the child welfare principles described in the **Children Act 1989**
- all staff to have an understanding of the social implications of disability
- holistic, needs-led assessments, incorporating the views of a range of professionals when necessary
- practical arrangements and strategies to improve inter-divisional and corporate and inter-agency work.

In particular, Standard 6.13 states: *“Adults’ and children’s services should be ready to work together to support you to uphold your child’s welfare. There should be co-operation between different services and agencies as necessary.”*

Examples of good practice highlighted in *A Jigsaw of Services* include:

- direct payment schemes
- multi-purpose centres which provide a range of services
- assessment form with prompts to guide workers to undertake holistic assessments
- disabled parents and their children enabled to engage, contribute, be understood and understand what is happening through the use of specialist help, peer support and advocates.

## **Valuing People: A New Strategy for Learning Disability for the 21st Century**

<http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf>

*Valuing People* sets out how the Government will provide new opportunities for children and adults with learning disabilities and their families to live full and independent lives as part of their local communities.

The Strategy’s four key principles of rights, independence, choice and inclusion lie at the heart of the Government’s proposals. The Strategy states that a person-centred approach will be essential to deliver real change in the lives of people with learning disabilities. Person-centred planning provides the single, multi-agency mechanism for achieving this. The Strategy states,

*“The Government’s objectives are:*

- *To enable people with learning disabilities to have access to a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary.*
- *To enable people with learning disabilities and their families to have greater choice and control over where and how they live.”*

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## **Good practice guidance on working with parents with learning disabilities**

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_075119](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_075119)

Parents with learning disabilities have the right to an assessment of their needs for support in their daily lives; such assessment should include any assistance required with parenting roles and tasks; parents should have their assessed needs met where eligible and considering available resources in line with **Fair Access to Care Services**.

Assessments should cover family and environmental factors, as well as parental capacity. Research tells us that family and community support networks are particularly important for parents with learning disabilities and their children. We also know that parents with learning disabilities are particularly likely to experience difficult housing situations and poverty. Both the **Common Assessment Framework** and the **Framework for the Assessment of Children in Need and their Families** require that family and environmental factors are covered.

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## **Supporting parents with learning disabilities**

Paragraph 7.40 of *Valuing People* states:

*The number of people with learning disabilities who are forming relationships and having children has steadily increased over the last 20 years. Parents with learning disabilities are amongst the most socially and economically disadvantaged groups. They are more likely than other parents to make heavy demands on child welfare services and have their children looked after by the local authority. People with learning disabilities can be good parents and provide their children with a good start in life, but may require considerable help to do so. This requires children and adult social services teams to work closely together to develop a common approach. Social services departments have a duty to safeguard the welfare of children, and in some circumstances a parent with learning disabilities will not be able to meet their child's needs. However, we believe this should not be the result of agencies not arranging for appropriate and timely support.*

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## Section 189(1) of the Housing Act 1996

<http://www.opsi.gov.uk/ACTS/acts1996/96052-ac.htm>

This states that an applicant will be accepted as having a priority need for housing if they are:

- a person with whom dependent children reside or might reasonably be expected to reside
- a person who 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.

## Think Family

[http://www.cabinetoffice.gov.uk/social\\_exclusion\\_task\\_force/families\\_at\\_risk.aspx](http://www.cabinetoffice.gov.uk/social_exclusion_task_force/families_at_risk.aspx)

*Think Family: Improving the life chances of families at risk* (2008) is the second report from the Cabinet Office's Social Exclusion Task Force review on families at risk. It 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 also outlines the key characteristics of a system that thinks family at all levels, from governance to the frontline.

It states that *"In a system that 'thinks family', both adults' and children's services join up around the needs of the family"*, and it sets out what this system would look like to families on the ground.

Services would:

- have no 'wrong door'
- look at the whole family
- build on family strengths
- provide support tailored to need.

It sets out a vision for the following:

- Individual needs to be looked at in the context of the whole family, so clients are seen not just as individuals but as parents or other family members.

*"Someone to turn to when our house boils over with emotions, someone who can sit and talk to us about how that could have been dealt with better. I think this is important because otherwise it leads to people blanking each other out and shouting at each other."*

(young carer)

- Support which is tailored to meet need so that families with the most complex needs receive the most intensive support.
- Services which start with a family's strengths. Practitioners work in partnership with families, recognising and promoting resilience and supporting them to build up aspirations and capabilities.
- Support that is provided needs to empower families to make their own decisions and to be involved in designing the help they need to achieve positive outcomes. Services build the capacity of family members to support each other.
- Encouraging all practitioners to 'think family' will allow risk to be identified earlier. Local commissioners will therefore need to decide how services will support the likely increase in numbers of referrals for preventative support. This might translate into a gradual shift in funding from crisis-led to preventative programmes.
- 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.

It sets out how change can be achieved at every level of the system.

- **Families at the centre** Families are involved in the design of their support wherever possible and empowered through devolved budgets and family-led decision making.
- **Integrated frontline delivery** Empowered and assertive practitioners provide tailored and joined-up support around the whole family. They identify needs early and proactively engage families.
- **Integrated processes** Shared assessments and information across agencies give a full picture of a family's needs and help ensure support is fully co-ordinated.
- **Integrated strategy** Joined-up planning and commissioning drive a focus on families at risk across all agencies.
- **Inter-agency governance** Accountability for family outcomes is clear, with strong leadership at the top and protocols setting out agreed responsibilities between agencies.

## **Documents giving further guidance on legislation relating to young carers**

Social Services Inspectorate (1995) *Young carers: something to think about*. Available from: <http://www.carersinformation.org.uk/showdoc.ihtml?id=421&zz>

Social Services Inspectorate (1996) *Young Carers Making a Start* contains practical guidance on assessments. Available from: <http://www.dh.gov.uk/en/AdvanceSearchResult/index.htm?searchTerms=young+carers++Making+a+start>

## **The health and well-being of young carers**

<http://www.scie.org.uk/publications/briefings/briefing11/index.asp>

## **Helping parents with a learning disability in their role as parents**

<http://www.scie.org.uk/publications/briefings/files/scare14.pdf>

## **Helping parents with a physical disability or sensory impairment in their role as parents**

<http://www.scie.org.uk/publications/briefings/briefing13/index.asp>

## **Parenting capacity and substance misuse**

<http://www.scie.org.uk/publications/briefings/briefing06/index.asp>

## **Supporting disabled parents and parents with additional support needs**

Morris J. and Wates M. *Social Care Institute for Excellence Knowledge Review 2006*  
<http://www.scie.org.uk/publications/knowledgereviews/kr11.pdf>

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# PART 3

## Key Principles of Practice

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### Key Principle 1

**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.**

#### Standard

- Young carers are treated as children first and, as such, have a right to feel happy and well, to have adequate leisure time, good emotional and physical health and a family life.
- Children who care have the same rights as all children:
  - Their welfare is paramount.
  - They have a right to be consulted about what they want.
  - They have a right to childhood.
  - They have a right to protection from significant harm.
- It is in children’s best interests to be brought up by their own families wherever possible.

*“Many young carers say that they felt that they were seen as a low priority by social services and other helping organisations. They were not in immediate danger – of abuse or anything like that – but were at risk of longer term repercussions through not being able to get the grades they deserve at school, missing out on enjoying the usual things of childhood or being a teenager, or of physical and mental health problems later on. These weren’t things that led to them getting much help.”*

(Commission for Social Care Inspection Unit, 2006)

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#### Think ‘whole family’

Families should be offered co-ordinated and timely support to prevent young carers from becoming children in need or children at risk. Those parents who have difficulties maintaining a positive relationship with their children should have access to appropriate support. Access to direct payments to support parenting needs should be offered where appropriate.

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## Performance indicators

**1.1** All providers of services for young carers have statements of purpose and accountability that clearly state the intention to prevent children undertaking inappropriate care and levels of responsibility. This will involve a collective responsibility for adults' and children's services to work to a joint protocol (Social Care Institute for Excellence, 2005) which means that universal services must include adults' services.

All agencies providing support to families where there is a member in need of care:

- have clear and accessible information for children and families
- have agreed inter-agency intervention strategies in place so that those requiring assistance with care needs feel able to seek help before a crisis is reached
- have agreed identification, referral and assessment protocols between adults' and children's services (including schools and health care workers) when working with families where there is potential for children to undertake inappropriate levels of care and responsibility
- are able to identify if a child is undertaking inappropriate levels of care and have procedures in place that can be implemented in order to offer a whole family assessment

*“Being a young carer does have a cost to you and your future; like being unable to do the sorts of things other children do, being under pressure and stress all the time, and suffering your own emotional and stress problems that begin to damage your own mental health for the future.”*

(Source: CSIU)

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### Resolving tensions between child and parent

There may be differences of view between children and parents about what constitute appropriate levels of care. This is highlighted in *Framework for the Assessment of Children in Need and their Families* (Department of Health, 2000 p.89):

*“Such differences may be out in the open or concealed. The resolution of such tensions will require good quality joint work between adult and children’s social services as well as co-operation from schools and health care workers.”*

*“My mum won’t accept support as she thinks she is OK, but it is me that ends up with it all.”*

(young carer)

- make use of the **Common Assessment Framework** to assist with identification by both adults' and children's services – questions should also be included within any Single Assessment Process to identify if a child may be caring
- offer staff training (including those working in Early Years) in joint working to identify and meet needs of young carers and their families.

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## Think parent

It is often assumed by professionals that children of disabled people are 'in need' even though the Children Act 1989 Guidance and Regulations state that children of disabled parents should not automatically be seen as 'in need'. Nonetheless, parents are often told: "Your child comes under the definition of a child in need because you are disabled, so we need to get the children and families section involved". Parents are constantly caught between the two departments and receive a service from neither.

(Disabled Parents Network quoted in The Education Network, 2005)

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- 1.2** All agencies implement inter-agency collaboration and planning at both strategic and service provision levels to be pro-active and consider how best to:
- identify and reach out to families in order to offer support to prevent inappropriate care being undertaken by children
  - intervene, if it is evident that inappropriate care is already happening, in a timely, flexible, appropriate, trustworthy way that is sensitive to the needs and wishes of the child and their family

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## Identification

Not all children who have ill or disabled parents or siblings take on caring roles or do so in ways that cause difficulties. Circumstances will vary. The important thing is that professionals work closely with the family and the young person so that reasonable steps can be taken to pre-empt likely problems and any emerging difficulties can be identified at an early stage.

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## The Single Assessment Process

The Single Assessment Process, introduced in the National Service Framework for older people, aims to make sure that people's care needs are assessed thoroughly and accurately, but without procedures being needlessly duplicated by different agencies.

<http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/SingleAssessmentProcess/fs/en>

- pull together flexible supportive care packages and management plans for the person who needs care, to prevent children from undertaking inappropriate physical or emotional care; review regularly

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### Local authority ‘lead person’

Each local authority should have a lead person who is in a position to negotiate at senior level with adults’ and children’s services and settle any funding disputes quickly.

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- address parents’ support needs before assessing their parenting capacity
- meet the needs of episodic illness and of those families who do not meet the statutory agency threshold of eligibility criteria for adults’ services but whose children are undertaking, or are likely to undertake, inappropriate care tasks
- support those children who wish to undertake some appropriate caring responsibilities and those who choose not to care.

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### Children’s and Young People’s Plans

Local partners should consider carefully the needs of young carers as part of their local needs assessment and, where appropriate, agree local targets and priorities for inclusion in their local area agreements. They should include these, together with the actions and activities needed to deliver them, in their Children’s and Young People’s Plan.

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- 1.3** If a child is **at risk**, families are offered timely and co-ordinated support to prevent the need for children and young people to be looked after, and the decision to look after a child is taken only when there are no appropriate alternatives.

### Parental mental illness

Encourage better information sharing between adult mental health services and children’s services to support parental responsibilities. Encourage assessment and planning in secondary mental health care, such as the Care Programme Approach, to include family situation and parental responsibilities.

(Cabinet Office, 2008)

*“When your mum goes into hospital you need private times like a family room. Mum’s depression may mean she doesn’t want to talk much but you just want to be near her.”*

(young carer)

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## Parental drug misuse

*Working Together to Safeguard Children* (DfES, 2006) recognised 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
  - Inter-agency 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 Drug Action Teams (DATs) or Drug and Alcohol Action Teams (DAATs) and other agencies that can assist in the assessment and outcomes.
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- 1.4** Adults' services are alert to child protection issues and support parents to keep their children safe.
- 1.5** There are mechanisms in place so that any assessment of a young carer under the **Framework for the Assessment of Children in Need and their Families** automatically triggers an assessment or review of the personal care needs and any parenting support for the person with a long-term illness or disability.

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## Ascertain what needs to change

Providing an assessment only for the child will not necessarily resolve the situation that has caused their referral. All assessments should ascertain **why** the child is caring and what needs to change in order to prevent them undertaking inappropriate levels of care and responsibility which impact on their own well-being.

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**1.6** Consideration and solutions will be offered to children who find themselves in caring situations which do or may involve lifting, handling or giving medication. This may include:

- risk assessments to ensure young carers do not come to any physical harm
- support and advice on administering medication and addressing any legal implications of doing so.

While the above may seem contrary to the notion of preventing inappropriate care, the reality is that many children do give medication and do find themselves needing to lift someone.

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### **Barriers and difficulties**

It may be difficult to engage with some families, and agencies must consider how best to meet need in such circumstances. It must also be recognised that being a young carer does not mean that a child or young person is automatically in need of protection. What it does signify is that services must be vigilant and ensure that the family *does not find itself in crisis*, resulting in child protection procedures being triggered because of a lack of effective support being provided to the parent.

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**1.7** There are services available to offer emotional support to young carers – either on a one-to-one basis or in a group – which are sensitive to individual needs, confidential, accessible and offer continuity and supported transition or exit.

*“It’s not what I have to do... it’s how I feel inside.”*

(young carer)

**1.8** All known young carers aged 16–17 years are offered an assessment for eligibility for direct payments, and services promote the fact that direct payments are available.

## Outcomes

- ✓ Young carers who are children in need are identified or feel able to ask for help, are listened to and offered direct services and, if needed, protection.
- ✓ Disabled parents are enabled where possible to bring up their children. Where children are unable to live with their parents, adults' and children's services can demonstrate that this is not as a result of lack of support to the parents.
- ✓ The child's caring role is assessed in terms of its impact on the child's development, and services are provided both to the child and to the person in need of care in order to reduce or prevent inappropriate levels of caring.
- ✓ Systems are in place and put into practice for agreed identification, referral and assessment protocols and service delivery between adults' and children's services.
- ✓ Steps are taken to provide children and young people with a safe environment wherever they are.
- ✓ Services are provided to support parental roles and responsibilities in order to safeguard and promote children's welfare.
- ✓ Healthy lifestyles are promoted for children and young people.
- ✓ Children's and young people's physical and mental health is supported.

### Prevention

The Carers' Strategy has a vision where high quality targeted support is accessible to those who need it and based on sound evidence of what works. Above all, it is one where prevention – protecting young people from falling into inappropriate caring – is the priority and a guiding principle behind the planning and delivery of services.

(Carers' Strategy, Department of Health, 2008)

*“People say you we have choice and can walk away. But we can't. It's our family. Sometimes we feel trapped. It's hard...”*

(young carer)

## Key Principle 2

**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.**

### Standard

- Assessments should not only identify regular individual personal care needs, but also consider the range of parenting, caring and family tasks that are needed when professional carers are not present and that may result in the child assuming responsibility.
- The development of cross-agency whole-family assessments should provide an opportunity for service providers to be proactive rather than reactive. It also provides for effective partnership working inter-departmentally, across agencies and helps to bridge the gap between children’s and adults’ services.

**The UNCRC**  
UNCRC Article 8  
specifies the child’s  
right to a family life.

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#### A Jigsaw of Services

*A Jigsaw of Services* (Department of Health, 2000) recommended a major shift in the approach to working with disabled parents. This included a recognition of the right of disabled people to be supported in fulfilling their roles and responsibilities as parents, and the development of policies and strategies to improve ‘joined-up working’ across adults’ and children’s service divisions and between agencies.

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#### Whole-family assessments

A whole family assessment brings together individual assessments to provide an overview of family strengths, risks, relationships and needs.

(Cabinet Office, 2008)

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*“Assessments are also important in order to meet the needs of us and our families. When doing an assessment it is important to understand how the condition or illness can affect the whole family and how families’ needs and individuals’ needs may differ but also affect each other.”*  
(young carer)

## Performance indicators

**2.1** Service providers of both children's and adults' services develop joint whole-family assessment protocols that focus on the following:

- i) How the assessment can support the person who needs care, including any parenting support needs. An assessment should not focus on what parents cannot do as a result of impairments, but on how environments can be changed and equipment and support provided to promote their independence and support their parenting role.
- ii) Recognising the specific needs of any young carer. (What additional services are needed to prevent the child caring inappropriately and do they need a service – eg, referral to young carers project, counselling or assessment of need under the **Framework for the Assessment of Children in Need**?)
- iii) Recognising the needs of the whole family (What is the impact of the illness or impairment on the family and the consequent needs of the whole family? What services could support the parent(s) in their parenting role?)
- iv) Recognising what environmental factors are having an adverse effect on the family, including housing, availability of local transport or shops. (What are the financial issues? For example, are benefits being claimed?)

**2.2** When a referral is made for a parent with a disability or illness, agencies consider whether there is a child in the family who is helping to provide care. If so, consider:

- What additional services are needed to prevent the child caring inappropriately?
- Does the parent need support in their parenting role?
- What can be offered to help the whole family?
- Does the child need to be offered an assessment under the **Framework for the Assessment of Children in Need** or the **Carers and Disabled Children Act 2000**? (See pages 19–22 and 25–27).

### Health professionals

Health professionals are likely to be the first people that a family turns to for help with an illness or disability. Whether you work in a hospital or community, with adults or children, you may be the only person who is able to ask the right questions to find out that a child is taking on caring responsibilities. Timely intervention could prevent a child undertaking inappropriate levels of care. Additionally, GP surgeries should have registers identifying carers, including young carers.

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## People with learning disabilities

*“Enable people with learning disabilities to have access to a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard and with additional support where necessary.”*

(Department of Health White Paper, 2001)

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- 2.3** When a referral is made for a child with a disability or illness, agencies consider whether there is another child in the family who is helping to provide care. If so, consider:
- What additional services are needed for the disabled child or parent carers to prevent the child caring inappropriately?
  - Does the parent need support in their parenting role?
  - What can be offered to help the whole family?
  - Does that child need to be offered an assessment under the **Framework for the Assessment of Children in Need** or the **Carers Act**?
- 2.4** There are mechanisms in place so that any assessment of a young carer under the **Framework for the Assessment of Children in Need** automatically triggers an assessment or review of personal care need and any parenting support for the person with a long-term illness or disability.

### Disabled Parents Network

Disabled Parents Network have published a series of briefings online including *Making a Care Plan to Meet Your Needs, Direct Payments and Disabled Parents, Maternity services and support for new parents*. They are available at: [www.disabledparentsnetwork.org.uk](http://www.disabledparentsnetwork.org.uk)

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## What needs to change?

Providing an assessment only for the child will not necessarily resolve the cause of referral. All assessments should ascertain why the child is caring and what needs to change in order to prevent inappropriate levels of care impacting on the child’s own well-being.

Those parents who have difficulties maintaining a positive relationship with their children should have access to appropriate support.

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## Supporting disabled parents and parents with additional support needs

The *Social Care Institute for Excellence Knowledge Review 2006* (Morris and Wates) consulted with disabled parents who 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
  - provide information and support in ways that are easily understood, as well as assistance and/or advocacy support where necessary.
  - deliver support that strengthens their parenting role, and this support should encompass the role of both fathers and mothers.
- 

*“Well, she came home from hospital and no one rang to check how we were coping. We weren't. They should have rung to check.”*

(young carer)

**2.5** Assessments and consequent care packages consider how support will:

- meet changing or episodic conditions
- include plans for crisis provision.

**2.6** Practice is inclusive and sensitive to cultural perceptions and needs.

In order to promote inclusive practices, it is important that families' lives should be understood from their cultural perspective. Special consideration must also be given to the particular barriers faced by individual families. (For example, refugees and asylum-seekers – see pages 5–8)

### **Hospital discharge plans**

Particular consideration should be given to the parenting needs of the client and any needs of children at the point of discharge from hospital.

- 2.7** Working partnerships with specialist agencies are in place to support children caring in families where there is problem drug and alcohol use. Drug-misusing parents are given appropriate access to drugs treatment support to prevent and reduce the harm caused to their children.
- 2.8** Training is provided for Early Years staff and integrated services offer support to parents to improve the well-being of very young children.
- 2.9** All services are accessible and enable parents to obtain – at the earliest point – user-friendly information regarding their rights and choices.
- 2.10** Local policies for eligibility and charging criteria are reviewed to ensure that a refusal to provide services does not result in a young carer taking on additional caring responsibilities.
- 2.11** The take-up and benefit of direct payments for disabled parents and parent carers of disabled children is monitored.
- 2.12** Agencies are familiar with the guidance checklists already available for whole-family assessments and use them effectively. (See pages 25–27)
- 2.13** Steps are taken to give families and children access to decent homes that meet any identified needs.

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## Housing

**Section 189(1) of the Housing Act 1996 states that a person with whom dependent children reside or might reasonably be expected to reside would have a priority need for housing.**

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- 2.14** Services are provided that can be sustainable and secure over time (e.g. continuing health care for those with a chronic illness).

### Think Family

**Embed, through the forthcoming National Drug Strategy, a strong focus on the harm that substance misuse (drugs and alcohol) causes to children and families. Set out steps to ensure that families affected by substance misuse are identified earlier and offered improved support, and promote a greater involvement of families in drug treatment.**

(Cabinet Office, 2008)

**2.15** All agencies that provide support for disabled clients carry out an audit of procedures, buildings and information to ensure that they meet the requirements of the **Disability Discrimination Act 1995**.

### **Making direct payments for assistance with parenting tasks and responsibilities**

The **Community Care (Direct Payments) Act 1989** made it possible for social services departments to provide direct payments in lieu of services to meet assessed needs. This could potentially include parenting needs. The **Health and Social Care Act 2001**, which came into force in 2002, requires councils to make a direct payment to anyone who has been assessed as needing services and who requests and is able to manage a direct payment, with assistance if necessary.

The **Health and Social Care Act 2001** also allows disabled parents to access direct payments to purchase services provided under the **Children Act 1989**, via an amended section 17a. This enables adult disability services, with input from children's and/or health services as and where appropriate, to put together a support package involving direct payments to support parenting and thereby safeguard the welfare of children. This should not automatically necessitate a separate children's assessment, however, since meeting the support needs of the adult with parenting responsibilities is intended to prevent the child becoming a child 'in need'.

The identification of a child who is regularly undertaking excessive or inappropriate care tasks (Wates, 2002) in respect of a disabled parent should automatically trigger an assessment of the adult's personal support needs, including any assistance needed with parenting tasks. However, assessment using the **Framework for the Assessment of Children in Need** should not take place as a matter of course, but only where it is deemed that certain needs of the child's are more likely to remain unmet even when the parental support needs have been addressed.

### **Keeping the Family in Mind**

*Keeping the Family in Mind* resource pack is aimed at anyone who works with parents with mental health problems, their children and their families. It is a multimedia package of training resources designed to raise awareness of the issues that families face. All the resources have been written and produced with the participation of young carers.

([www.barnardos.org.uk/resources/research\\_and\\_publications.htm](http://www.barnardos.org.uk/resources/research_and_publications.htm))

*"The main problem is that I am not ill all the time. That is why I do not get any support. I asked them to take into account the effect my illness has on my daughter as a young carer and they agreed to give her five minutes of their time. And this has not happened until this day."*

(disabled parent)

## Outcomes

- ✓ Effective and flexible services that are responsive to the changing needs of disabled parents or child are delivered, so that children do not have to take on inappropriate caring roles and responsibilities and the impact on the whole family of illness or impairment is reduced or resolved.
- ✓ Disabled parents are enabled where possible to bring up their children. Where children are unable to live with their parents, adults' and children's services can demonstrate that this is not as a result of lack of support.
- ✓ Assessments for disabled parents identify and address any needs of children who are caring and the impact on the family.
- ✓ Likewise, effective and flexible services are responsive to the changing needs of disabled or ill children so that siblings do not have to take on inappropriate caring roles and responsibilities, and the impact of the illness or impairment on the whole family is reduced or resolved.
- ✓ Contingency plans are in place to manage emergency changes.
- ✓ Disabled or chronically sick parents are supported in fulfilling their roles and responsibilities as parents. (Those parents who have difficulties maintaining a positive relationship with their children have access to appropriate support.)
- ✓ Assessments for children with disabilities or chronic illness and their parent carers identify and address any needs of siblings who are caring and the impact on the family.
- ✓ Assessments and services are inclusive and culturally sensitive and appropriate. Users and helpers are matched appropriately and no discrimination is made in access to services on the grounds of disability.
- ✓ Adults' and children's services work together to support the family and to uphold a child's welfare. There is co-operation between different services and agencies, including housing, so that children can be brought up in their own family wherever possible.

### **Joined-up, whole-family support**

**The 2008 Carers' Strategy has as an aim for 2018, that all areas will be delivering better joined-up, whole-family support to families affected by illness, disability or substance misuse who have young carers. Assessments and support offered will take proper account of the need to protect children from inappropriate caring, while families and parents themselves will have a greater say in the shaping of services around them.**

(Carers' Strategy, Department of Health, 2008)

## Key Principle 3

**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.**

### Standard

- All young carers and their families are informed and given equal opportunity to express their views with regard to their own needs, their responsibilities, the services with which they are provided, policy development, planning and review.
- Working in partnership with young carers and their families is vital in developing coherent, efficient services to meet their needs. Effective consultation should empower children and their families to make decisions and choices, supporting them to feel more able and confident to approach agencies for help when it is needed. Consultation needs to be undertaken at all levels so that the needs of individual families are met and local policy, practice and service delivery are influenced.

### Performance indicators

- 3.1** Young carers and their families receive easily understood information about assessments of their needs, the full range of relevant services available, how the services work and what to do if they wish to complain.

If needed, the services can arrange access to trained interpreters and signers.

Information must be positive, comprehensive, accurate, appropriate, accessible and responsive so that children and families know what services are available and are able to make informed choices. It should be presented appropriately and in ways that take account of age, disability and racial, cultural and linguistic backgrounds.

#### Empowering families

Families know most about their own situation. They should be *empowered to shape the package of support* that they feel will help them achieve the best outcomes. Wherever possible families, including extended family members, should make decisions about their own lives and agree their own responses to challenging circumstances.

(Cabinet Office, 2008)

*“Real service improvement is only attainable through involving children and young people and listening to their views... Children, young people and families themselves should have far more say in the design and delivery of the services they use.”*

(Source: Every Child Matters)

*“When people do something without asking, it won’t be right.”*

(young carer)

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## Early intervention

**Early interventions can prevent ‘young caring’ becoming established. Emphasis should be on preventing children from taking on inappropriate caring responsibilities.**

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- 3.2** All young carers and their families have access to effective advocacy services if required.

Access to signing, interpreting or translation should also be made available if needed.

- 3.3** Effective, meaningful participation and consultation techniques are promoted across services and used to ascertain the wishes and feelings of the children and their families so that the right services and packages of care can be developed.

Young people, families and user groups need to know how to get their views heard and receive meaningful feedback. It is essential that age- and culturally-appropriate participation techniques and materials are used. Local services need to be pro-active to ensure that young people who do not identify themselves as carers and young carers from hard-to-reach communities are involved – young carers in rural areas, young carers from black communities and other ethnic groups, people with communication difficulties, travellers, refugees and asylum-seekers.

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## Signposting

**Where an agency does not have the appropriate expertise, easy signposting to other sources of expert information should be available.**

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- 3.4** Services provide clear written policies about what they do with information that they have about children and families and who they share this with. Records are easily accessible to young carers and their families.

*“Enable people with learning disabilities and their families to have greater choice and control over where and how they live.”*

(Department of Health White Paper, 2001)

### The UNCRC

**UNCRC Article 12 specifies that children have a right to say what they think should happen when decisions are being made that affect them, and to have their opinions taken into account.**

**UNCRC Article 17 supports children’s right to information.**

*“How are we supposed to understand about her mental illness and her moods when no one bothers to explain it to us?”*

(young carer)

## Outcomes

- ✓ Parents and children have information about processes and services available in appropriate formats and different languages so that they can make well-informed choices.
- ✓ Parents and parents-to-be have sufficient information about services so that they can make well-informed choices.
- ✓ Families have clear information about how to raise a concern or make a complaint, if needed.
- ✓ Children and families are involved in the development, regular evaluation and updating of information provided by the service.
- ✓ Children and young people are helped to manage changes and respond to challenges in their lives.
- ✓ Children and young people are encouraged to participate in decision-making.

*“Effective information sharing is not just about the flow of communication between service provider and the user, it is also (and sometimes more importantly) about the flow of information between agencies.”*

(Laming, 2003)

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### The National Young Carers Forum

The Children’s Society, in partnership with The Princess Royal Trust for Carers and funded by the DCSF, has facilitated the establishment of the first national young carers forum for England. Members of the forum have made a training DVD called *Listening to Young Carers*, in which young people talk about the issues they face and share solutions that will help improve their lives.

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## Key Principle 4

**Young carers will have the same access to education and career choices as their peers.**

### Standard

Schools and colleges take responsibility to identify young carers at an early stage and where possible have a named staff member with lead responsibility for young carers: a) to ensure that they have the same access to a full education and career choices as their peers; and b) to be responsible for promoting and co-ordinating the support they need and liaising with other agencies as appropriate.

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#### Managing behaviour and attendance

This is recommended by the Department for Children, Schools and Families (DCSF) in *Advice to Schools and Local Authorities on Managing Behaviour and Attendance: groups of pupils at particular risk* (DCSF, 2006). The designated teacher or member of staff is responsible for promoting and co-ordinating support and liaises with other agencies as appropriate. Schools should ensure that full use is made of the available support services: for example, education welfare, the Youth Service, social services and Connexions. Staff should be aware that young carers are entitled to an assessment of their own needs from children's services, and that joint working with adults' services will enable help to be provided that could benefit the whole family.

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School attendance is an integral part of the work to promote pupils' welfare, ensure that pupils succeed whilst they are at school and have the widest possible range of opportunities open to them beyond school. Schools should be monitoring all pupils' attendance and identifying those who are developing patterns of

#### The UNCRC

UNCRC Articles 28 and 29 state that children and young people have the right to the best available education and to opportunities to develop their personality and their mental and physical abilities to their fullest potential.

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

(young carer)

absence and persistent absence, which can be an indicator of underlying needs. They should then try to work with the pupils and their families to address those needs and resolve the underlying causes of the absence.

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### **Educational performance**

Many young carers have problems at school, including poor educational performance and difficulty fitting in with their peers. Such problems may be a consequence of poor attendance and the pressure and stress caused by their caring responsibilities. Although there has been a gradual decrease in absence from school among young carers since 1995, between 13 per cent of those of primary school age and 27 per cent of those of secondary school age are still experiencing some problems at school (Dearden and Becker, 2004). In addition, when families include someone with a disability, the family income is likely to be lower than average. This may affect the young person's opportunities for further education. (**Carers (Equal Opportunities) Act, 2004**)

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*“Young carers often make enormous efforts to manage their caring responsibilities and maintain full school attendance. However, some may struggle to cope all the time and subsequently their education, physical and mental health may be affected. Young carers can often feel as if they have somehow failed or feel extremely guilty for not coping.”*

(Baker, 2002)

## **Performance indicators**

- 4.1** Governing bodies in schools make provision for policy and practice that supports young carers and promotes good communication with their families, by having inclusive policies that enable the identification of young carers and that deliver effective methods of supporting them to achieve their full potential. Support might usefully be considered as part of the Healthy Schools Programme.

This does not necessarily entail writing new policies (although in some cases it will) but it does involve ensuring that those policies and practices already in place recognise young carers' needs. For example, inclusive anti-bullying policies that work, and inclusive practices that avoid stigmatisation and raise the self-esteem of children who are young carers.

It is also important that the effectiveness of these policies is monitored.

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## Schools and identification

*Caring about Carers* (Department of Health, 1999) recognised schools as one of the most likely places where young carers who are not already known to statutory authorities can be identified and then helped.

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### Find a local project

Schools can find out where their nearest local young carers project is at [www.youngcarer.com](http://www.youngcarer.com)

- 4.2** Schools and colleges provide clear, accessible, up-to-date information regarding health issues and local community services to all students. Young carers are signposted to where they can gain additional support for themselves and their family outside school.

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## Community notice boards

Young carers have expressed the need for notice boards in their school/community displaying up-to-date information, including:

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

The information on the notice board can also be used as a tool to promote:

- awareness within the school/community of young carers and their families
  - positive information about disability and illnesses that affect many families.
- 

## Messages from young carers

*“Teachers need to be taught awareness of disabilities and what young carers do. They need to know that caring is tiring and can have its crises, and that they need to be flexible in what they expect of children and young people who have caring responsibilities as well as responsibility to do school work. Young carers can’t always keep home and school separate.”*

*“Staff need to be aware that young carers will sometimes be stressed, which might either make them lose their temper at school, or perhaps want to be left alone at school and not be asked lots of questions.”*

*“It is important that staff notice when you may need to talk or need help, but that they shouldn’t keep asking if you’re OK.”*

*“I didn’t want to be treated differently.”*

(source: Commission for Social Care Inspection Unit, 2006)

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## Social and Emotional Aspects of Learning (SEAL)

Although SEAL aims to develop the social and emotional skills of all children, it may be of particular benefit to young carers. The small group element covers issues such as anger management, handling relationships, lack of confidence and bullying.

Over 60 per cent of primary schools are now engaging with the SEAL programme and the first 15 to 20 per cent of secondary schools are expected to start implementing the SEAL programme by July 2008.

The National Healthy Schools Programme guidance on emotional health and well-being, published in 2007, highlights and strongly supports the use of the SEAL programme in schools.

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- 4.3** Schools and colleges are accessible to parents who are disabled or have a long-term illness. Communication strategies include provision for any parent with a visual, hearing or communication impairment (as covered in the **Disability Discrimination Act 1995** with regard to access to goods, services and facilities).
- 

### Accessibility

This can mean physical access such as ramps, dropped kerbs, parking spaces, lifts, a choice of types of chair to sit on. It can also mean accessible communication such as asking parents in what format they would prefer school reports, whether they would like sign language interpretation at meetings with teachers, telephoning parents who are unable to come to meetings, etc. (Morris, 2003)

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- 4.4** The curriculum promotes a fuller understanding, acceptance of and respect for, the issues surrounding disabilities and caring and also promotes positive images of disability and impairment.

### Keeping in touch

Schools need to understand that being able to keep in touch is important for both the person being looked after, who may be left home alone, and their young carer.

(Commission for Social Care Inspection Unit, 2006)

- 4.5** Staff have access to information and training to enable them to recognise the indications that a child has a caring responsibility and to increase their understanding of such responsibilities.

Access to awareness-raising sessions and training should be available to all teachers and relevant non-teaching staff. Be aware that training sessions may raise issues for any staff who were young carers themselves.

- 4.6** Individual plans recognise the child/young person's specific needs as a young carer.

For example:

- providing support to enable them to complete their homework and coursework
- facilitating smooth transition periods, such as moving from primary to secondary school, or from secondary school to college
- providing access to a telephone while in school/college
- notifying an examination authority of a young carer's circumstances
- providing education out of school, if this is required.

Young carers should have opportunities to make their views and needs known so that these can be fully considered when additional support is being planned and provided.

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### Supporting pupils who have been absent

If a child has been absent from school for some time, ask the child what support they would like to receive that may help them feel more confident about returning to school. Remember to ask if the child would feel less anxious leaving the person they care for if they were given access to a telephone during the school day. Also ask the parent(s) and child if they can identify a teacher who can be given details of their caring responsibilities.

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*“It is also important that all your teachers know about this, without you having to keep telling new people all about being a carer whenever you don't make a school work deadline because of it: it feels like I've got to explain myself so many times.”*

(young carer quoted in Commission for Social Care Inspection Unit, 2006)

### Disabled parents and schools

*They Said What?* and *Disabled Parents and Schools*, both by Jenny Morris, explain the common experiences of disabled parents when seeking help from social services or trying to support their child's education.

- 4.7** Local authorities consider how best to support those parents who find it difficult to escort younger children to school.

Being disabled or ill can result in great difficulties for parents to get their children to and from school and to fulfil their responsibility to ensure their children attend school.

- 4.8** Admission authorities consider the responsibilities of young carers and the impact of any family disability or illness on those young carers when setting admission criteria for their schools.

Many young carers attending secondary school are responsible for escorting younger siblings to primary school when a parent is unable to escort them. This can cause difficulties for the older child, particularly when young children do not attend schools close to or en route to the older child's school. Also many young carers wish to get home early to be with a parent and their journey will take longer if they do not live in their school's catchment area. This can result in lateness or poor attendance.

- 4.9** Further Education (FE) colleges should be aware of young carers' issues and have policies and practice in place to support them, so that young carers are not disadvantaged and are enabled to have equal opportunities to attend FE courses if they wish. Flexibility and/or support with coursework demands may be needed at times for some young carers.

Many young carers give up on pursuing their own aspirations because they are worried about what will happen if they are not around to support their family. This is especially difficult for older young carers and makes the transition to adulthood particularly difficult (Frank et al, 1999). If a young person has experienced lost opportunities in gaining necessary qualifications, consideration should be given as to how they can be assisted to return to education and have a second chance at obtaining qualifications.

### **Escorting younger children 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.

### **School Admissions Code**

*"It is acceptable to give higher priority to children or families where there is a social or medical need (for example where one or both parents or the child has a disability that may make travel to a school further away more difficult)."*

Para 2.25 School Admissions Code (DCSF, 2007)

*"If we are at FE College and study over 21 hours a week, even though we are still caring all hours, we cannot get Carers' Allowance."*

(young carer)

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## Education Maintenance Allowance (EMA)

EMA is a weekly payment of up to £30 per week for eligible learners attending a valid learning programme; EMA is paid directly to the young person and can help with the day-to-day costs of staying in learning.

### EMA suggested good practice:

EMA Guidance for learning providers advises them to consider whether a young person has any caring responsibilities that have an on-going effect on their attendance; where necessary providers should explore solutions personally with the young person.

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*“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, 2000)

## Young carers give top ten tips for schools

1. Recognise that our responsibility as carers can affect our education and schoolwork.
2. Find out about us, what we need and how we are not like other students.
3. Take time to find out about individual problems at home. Sometimes we're too embarrassed to tell you ourselves.
4. Don't automatically punish us if we're late. Sometimes we can't help being late because we're helping out at home.
5. Provide more support such as lunchtime drop-ins or homework clubs.
6. Be flexible – give us more time and help to do homework or coursework.
7. Include information about young carers and disability issues in PHSE lessons.
8. Let us phone parents if we need to find out if they are OK.
9. 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.
10. Ensure teachers are offered training on young carers and disability issues both at university and on INSET days.

Source: Young Carers Festival 2006

*“Help us by extending coursework deadlines if we need it.”*

(young carer)

## Outcomes

- ✓ Children whose parents or other family members have specific needs arising out of disability or health conditions enjoy the same life chances as all other children in the locality.
- ✓ Young carers are enabled and encouraged to attend and enjoy school.
- ✓ Educational provision is made for those young carers whose attendance and education has been interrupted.
- ✓ Parents and carers are supported to enable their children to attend school and to enjoy and achieve their full potential.
- ✓ Young people are prepared for working life.
- ✓ Action is taken to reduce poor school attendance.
- ✓ Schools are fully accessible and have inclusive communication practices in place.
- ✓ The positive aspects of caring are recognised and valued.

*“I used to help out in the classroom occasionally and this was seen as a positive experience for the children who had never met a wheelchair user before. The school also invited other disabled speakers to talk with children from time to time.”*

(parent)

# Key Principle 5

**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.**

## Standard

■ All multi-agency strategies, needs assessments and Children and Young People's Plans based upon them address the need for ongoing training for staff and monitoring and reviewing of services both at strategic and individual levels.

## Performance indicators

**5.1** Services provide training for staff that develops a common understanding of the issues surrounding young carers and their families and equips frontline staff with the confidence and skills to address them.

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: teaching staff, support staff, GPs, youth workers, social workers (children's and adults' services), play workers, health visitors, hospital staff, etc.

Training content should include:

- the principles of whole-family working
- information on legislation and guidance
- the principles of effective partnership working between agencies, young carers and their families
- the importance of effective service delivery that explores the needs of individuals with personal care needs, their parenting role and the needs of the young carer
- the promotion of inclusivity.

### The UNCRC

UNCRC Article 3 states that all actions concerning children must have the best interest of the child as their primary concern.

UNCRC Article 17 supports the right to information.

### Core training

*Every Child Matters* commits the Government to workforce reform to deliver: *"a common core of training for those who work solely with children and families and those who have wider roles (such as GPs and the police) to help secure a consistent response to children's, parents' and families' needs and a better understanding of professional roles"*.

- 5.2** The Key Principles of Practice are used to support services to develop monitoring and evaluation tools and to ensure consistency.

The monitoring and evaluation of services will ensure that the best possible outcomes for young carers and their families are secured. Service providers are accountable for their actions – ie the provision of effective and targeted services, information or funds and the resources they manage.

- 5.3** The take-up and benefit of direct payments for disabled parents and parent carers of disabled children is monitored.

Monitoring should include:

- how effectively direct payments are used to provide support for a disabled parent's own care needs and for any identified parenting support needs
- whether direct payments are resulting in users having increased independence, greater flexibility and more control over their own lives.

### **Universal services**

**Universal services – schools, general practitioners, hospitals – have a vital role to play in young carers' lives. The support, understanding and practical guidance young carers receive through these settings can make a significant difference to their lives. Where it is lacking, young carers say it adds substantially to the pressures and problems they face.**

(Carers' Strategy, Department of Health, 2008)

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### **Joined-up support**

**Frontline staff across both children's and adults' services should be empowered to provide tailored and joined-up support. They should be given the flexibility to look beyond their normal remit and use their professional judgement to decide how to work in the most effective way for families. This might involve taking on a lead professional role, adapting an intervention to take account of family circumstances, or engaging clients with a specialist or targeted service. The role of practitioners in supporting the wider family should be acknowledged and applauded.**

(Cabinet Office, 2008)

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- 5.4** Monitoring through contracting, audit and quality assurance schemes is implemented for all services.

All agencies that provide for disabled clients and their families carry out an audit of procedures, buildings and information to ensure they meet requirements of the **Disability Discrimination Act 1995**.

- 5.5** Young carers and their families have opportunities to be involved in strategic monitoring and evaluation programmes and have sufficient power to influence policy, practice and funding.
- 5.6** Families have clear information about how to raise a concern or make a complaint, if needed.
- 5.7** Each agency records the number of children and young people identified as young carers, the resulting services put in place to prevent or reduce inappropriate levels of caring, and any increase in whole-family assessments.
- 5.8** Ways of securing long-term funding are explored both for realistic staffing levels and for direct work.

*“My mum has mental illness, but no one told me why she was acting so weird. None of the doctors told me. It was scary. I had to find out for myself. They didn’t think how I was feeling and worrying.”*

(young carer)

## Outcomes

- ✓ Staff at all levels in all departments and agencies have an understanding of the social consequences of disability and are aware of the potential impact of the caring role on childhood.
- ✓ Relevant cross-agency training on whole-family and joint working is accessible to frontline staff.
- ✓ Clear monitoring and review processes are in place and recorded as part of any assessment or care plan.
- ✓ The take up and benefit of direct payments improves outcomes for families and children.
- ✓ Audit information is available on the numbers of assessments that have a whole-family focus and result in a reduction in a child’s caring role.
- ✓ Families know who to contact to seek a review or raise any concerns.
- ✓ Partnership working with other agencies, including across adults’ and children’s services, will help staff gain a fuller picture of the family and sharpen the focus on what is needed to improve outcomes. Whatever their role in delivering services, all frontline practitioners should be able to understand how their engagement with an individual fits in with other support that the family may be receiving.

### Front-line services

*“The vision for 2018 is one in which professionals in our front-line services who are in most regular contact with young people have the knowledge they need to identify problems early and encourage young carers to come forward for the help they may need.”*

(Carers’ Strategy, Department of Health, 2008)

## Key Principle 6

**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.**

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 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.

*“Each young carer should get a regular phone call from someone they know and trust, to check up on how they are doing and whether they need any more help.”*

(young carer quoted in Commission for Social Care Inspection Unit, 2006)

### Standard

■ 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.

### Performance indicators

**6.1** Each local authority has a project(s) or direct service(s) to which it can refer young carers, if needed, giving young carers access to specialist group or one-to-one support.

Projects and direct support services for children help reduce both the sense of isolation experienced by many young carers and their families and the stigma that young carers often feel, particularly when caring for a parent(s) with mental health problems, or problem drug or alcohol use.

*“...It’s knowing that there is all this group behind you – there when you are feeling a bit low and all you have to do is phone someone up and you know that you have always got people stood behind you, who are caring for you...”*

(young carer)

- 6.2** Services and projects adhere to agreed policies regarding recruitment and selection procedures (including Criminal Records Bureau checks), child protection policies, health and safety procedures (including recorded risk assessments, record keeping and data protection, confidentiality, etc) as required.

Reference to the provision of direct services to meet the needs of young carers should be included in Children and Young People's Plans. Contracts and service agreements between providers and commissioning authorities should have clarity of purpose and ensure procedures are in place for safeguarding children.

- 6.3** All staff or volunteers are supported, trained and accountable.

Agencies need to ensure that staff have the appropriate qualifications and skills to support children and families and engage in direct work. All staff and volunteers should be offered an induction process, relevant training, supervision and performance reviews.

Statutory services should involve voluntary sector services in strategic planning, and relevant joint training to promote partnership working.

- 6.4** Services developed are needs-led, according to user groups and identified local resource needs.

Meaningful and accessible processes should be offered to children and families in order to enable their participation and empowerment. Children and families should be able to communicate their views and needs in order to influence the way policies and services are designed and delivered to best meet their needs.

*“Children, young people and families themselves should have far more say in the design and delivery of the services they use.”*

(HM Government, 2003)

- 6.5** Direct services and projects consider how they can best work together to support the family as a whole and develop practice that:

- is fully inclusive of all children and young people
- recognises that the needs of young carers and their families may be complex, requiring involvement or expertise from more than one support service or project
- lends support which helps young carers move out of inappropriate/excessive caring roles

- respects diversity
- acknowledges the needs of the family member who needs care (parent, sibling or other)
- advocates on behalf of the child, parent or family, or signposts them to partnership agencies who can do so.

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### **Being pro-active**

Whole-family working involves working towards being pro-active rather than reactive. It also involves developing thinking and practice that should prevent inappropriate levels of caring and responsibility being carried out by any child, that impact on their own well-being and development.

It is acknowledged that disabled parents hesitate to approach social services departments for support. At worst, parents may fear that their children will be removed from home. Young carers projects or services that provide support for the whole family may help to allay and address these anxieties and signpost parents to other support services. Projects and services should have partnerships or processes to advocate for the whole family both at policy and service levels and at an individual case level to:

- meet identified care needs
- meet any parenting needs
- reduce or prevent levels of inappropriate care by a child.

### **Sibling carers**

Remember to consider how to meet the needs of families where a child is caring for a disabled or ill sibling.

### **Parenting support**

Projects may wish to set up parenting peer support groups, make links with other local parenting support groups and with parent carer groups for families where a child has a disability or illness.

- 6.6** Steering group and/or management committee membership includes representatives from adults' services, adult users, disability and mental health groups, Connexions, health and community care providers, parenting organisations and other relevant agencies.

- 6.7** Children and young people are involved in planning the type of service they need, with evaluation and monitoring processes in place that include user feedback to inform development of the project's services.

Involving young people in the planning of services and delivery of activities or services could be achieved via a young carers forum or planning group. As well as developing self-confidence and team working skills, it promotes life skills and assists with developing coping strategies and resilience.

- 6.8** Services are provided that provide experiences and activities which aim to enhance young carers' mental health and social networks.

- 6.9** Services are inclusive and culturally sensitive, building links with those groups who support minority groups in the locality.

Special consideration should be given to reach out to specific groups to ensure inclusive working practice:

- black and minority ethnic groups
- refugees and asylum-seekers
- children in families where there is parental drug and alcohol misuse
- families living in rural areas with limited transport or direct access to drop-in or community services.

To support families and raise awareness of the work of project and needs of these families, links should be built with:

- family support centres
- parenting support groups
- minority support groups
- community groups
- extended services
- children's centres

and also with:

- Citizens Advice Bureau
- Benefits Agency

## Monitoring

Agencies need to have mechanisms in place to review, monitor and evaluate the services they provide and report back to funders or referral agencies.

## Meeting identified additional needs

Support is provided for children and young people having difficulties in developing and maintaining positive relationships with others or at risk of serial truancy or offending.

- 6.10** Services offer a safe and non-judgmental environment where young carers have the opportunity to talk over important decisions, to share feelings and confidences and to exchange information and knowledge with people they trust.

*“It helps to meet and talk with others who are in the same situation and know how you feel.”*

(young carer)

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### Websites

The Princess Royal Trust for Carers has developed a UK-wide online resource for young carers – [www.youngcarers.net](http://www.youngcarers.net) – which provides information tailored to their needs and inter-active support via email, moderated message boards and supervised chatroom sessions.

[www.childrensociety.org.uk/youngcarers](http://www.childrensociety.org.uk/youngcarers) has a UK-wide database of young carers projects, plus information and resources for professionals.

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- 6.11** Projects develop advocacy services or work with existing providers of advocacy. Advocates are well matched to the individual needs, culture and ethnicity of the young carer who, wherever possible, has some choice in his/her advocate.

Advocacy is a valuable service for supporting families and young people. If a parent is debilitated, vulnerable or finds communication difficult because of their illness, an advocacy service may be able to assist them in accessing information, support and services. Young carers can also benefit from an advocacy service that helps them articulate their own needs and understand systems and jargon. Advocacy can support people in speaking for themselves or in presenting their views for them, and assist them in making informed and free choices.

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### Counselling services

Any service described as a counselling service should be delivered by suitably qualified professionals supported or accredited by a recognised professional body such as the British Association of Counselling, and should be competent to address the young carer’s culture, religion, preferred language, age, gender, sexuality and disability.

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*“The project helps... When I talk to someone, it makes me feel better... It helps you to get what’s inside of you... out.”*

(young carer)

## Outcomes

- ✓ Children and young people have access to an appropriate range of support to meet identified needs.
- ✓ The work of projects or services promotes practice that works towards preventing children undertaking levels of care that impact on their own physical and emotional well-being and educational opportunities.
- ✓ Projects continue to safeguard the emotional and physical well-being of young carers by supporting their developmental needs as required and projects meet the five outcomes of **Every Child Matters**:
  - staying safe:
  - enjoying and achieving
  - being healthy
  - making a positive contribution
  - economic well-being.
- ✓ Services delivered by projects are family-focused and meet the needs of both the child and the person in need of care, including parenting support.
- ✓ Disabled parents and parent carers feel able to ask for support at a much earlier stage before a crisis is reached and before levels of caring impact on their children.
- ✓ Young carers benefit not only from support given directly to them by projects but also from additional support being given or negotiated for their parent(s) or brother or sister.
- ✓ There is a reduction in the sense of isolation experienced by many young carers and their families and reduction in the stigma that young carers often feel, particularly when caring for a parent(s) with mental health problems or problem drug or alcohol use.
- ✓ Local policies and practice are influenced and work towards preventing children caring inappropriately at levels that impact on their own development.

*“These groups are important because they give you days to escape your responsibilities and have time for yourself, with other people who understand what you were going through. It is not activities and things to do that were important about these groups, but just being with people who understand, ‘just knowing how you feel’.”*

(young carer)

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## Web resources

- www.youngcarer.com** The Children's Society's Young Carers Initiative includes a database of local Young Carers Services and the DCSF Principles of Practice for working with young carers. A full list of all support organisations can be found on this site at <http://www.youngcarer.com/showPage.php?file=1111536025.htm>
- www.youngcarers.net** The Princess Royal Trust for Carers young carers website offers online support to young carers and includes a section for professionals.
- www.disabledparentsnetwork.org.uk** Disabled Parents Network is the leading organisation advocating for the rights of disabled parents. The website includes information on the legal rights of disabled parents.

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These **key principles of practice** are an invaluable tool for policy makers and practitioners. As a statement of the essential values and common understanding that should underpin all support for young carers and their families, they give clarity, direction and purpose to professional practice. The **key principles** will also be a vital resource for policy makers and practitioners when developing and providing services and can be used to measure success across departments and agencies.

Threading the **key principles** throughout practice will also:

- support inter-agency joint practice and vital joint working between adults' services and children's services
- encourage young carers and families to come forward and self-refer at an early stage
- make the identification and assessment of any needs holistic and more effective
- support disabled parents' entitlements to assessments and services, including any parenting support needs
- work towards ensuring that children do not take on inappropriate roles and responsibilities
- work towards ensuring young carers and their families receive the same high standards of support and services wherever they are in the country
- influence change and clarify lines of accountability.

The Children's Society's Include Project has a track record of delivering quality training and information to agencies working to support young carers and their families. Find out more at [www.youngcarer.com](http://www.youngcarer.com) or telephone 01962 711511.

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