



## Young carers: personalisation and *whole family* approaches

26th October 2011

## ABOUT THIS PAPER

### Status

This paper brings together some key practice points along with practical examples and indicators of useful resources to help inform local practice, encourage discussion and improve outcomes. It does not seek to amend or replace existing statutory guidance that may be in place. Rather, it offers some signposts to effective practice and partnership working with a focus on improved outcomes for young carers and their families that can be shared and taken forward locally in line with local needs and circumstances.

Current legal frameworks and guidance are not reproduced within this paper. These frameworks are currently subject to review and a proper understanding of them is important when considering local policy and practice in what is potentially a complicated area. Summary information and comment about these frameworks can be found in the following:

- *Key Principles of Practice for Young Carers and their Families*. The Children's Society 2008.
- *Carers and their Rights - the law relating to Carers* (4th edition) Luke Clements in conjunction with Carers UK 2011

Where there is local uncertainty, reference should always be made to the source documents where appropriate and legal advice sought as needed.

### Focus

The focus of this paper is on young carers and how personalisation and whole family approaches can support them to have the opportunities that other young people enjoy. Partnership working between adult and children's services is essential in ensuring that young carers are identified and their needs addressed. This paper aims to look in particular at the responsibilities of Adult Social Care within this partnership and to share local experience and learning of personalised whole family approaches. It therefore focuses specifically on young carers who care for a disabled adult, who in most instances will be a parent. It brings together some key practice points along with practical examples.

Its intended audiences are: Directors of Adult and Children's services, Lead Members, Carers Leads, Commissioners, Health and Well-Being Partnerships and Carers and Children's Organisations.

This paper has been developed and funded in relation to England. The content may also be relevant within devolved administrations.

### Young Carers – a shared understanding

The central issues are those of recognition, adverse impact and support, including emotional support. This approach relies on the premise, within a whole family approach, that:

*"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 emotional or physical well being or educational achievement and life chances"*<sup>1</sup>

**Source: Working together to support young carers 2009<sup>2</sup>**

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## Foreword

***Councils should... 'be mindful, when assessing adults, of young carers to make sure they are not being asked to provide inappropriate levels of care.'***

*A vision for adult social care: Capable communities and active citizens. DH November 2010*

Every day significant numbers of children take on varying levels of care and support for adults. Helping out in the family can be a positive experience and a normal part of family life, but for some children the level of care giving and responsibility is such that it impacts on their emotional and physical well being, their educational achievements and their life chances. Whilst children's services clearly have an important role to play in supporting young carers it is often the person working with a parent who is best placed to identify issues arising for children, to prevent levels of unacceptable caring and promote the child's wellbeing. Thinking '*whole family*' when addressing adult support needs can help ensure that parents are supported in their parenting role and that children are free to develop emotionally and physically and enjoy and achieve in life.

Personalisation offers the opportunity to develop more holistic and flexible approaches to designing support that involves and benefits the whole family, and responds to each family's unique needs and strengths. *Think Local Act Personal*, the 2011 sector wide commitment to moving forward with personalisation and community based support, emphasises the importance of delivering whole family services which look at supporting families across health and social care, in an integrated, flexible way.

The 2009 Local Model Memorandum of Understanding: *Working together to Support Young Carers* from ADASS and ADCS provides a clear framework for partnership working between adult and children's services to develop and provide personalised and joined up support for young carers and their families.

The government's recent update to the carers strategy states that '*personalisation and a whole-family approach are complementary*'. This paper focuses on practical ways of developing these approaches. It includes many practical examples to help inform local practice and encourage discussion and we are grateful to all the people who provided examples and resources and contributed to the writing of this paper.

Directors of Adult Social Services and Directors of Children's services are encouraged to use these resource materials to help inform the development of local practice in ways that enable adult and children's social care to work fully in partnership with health, education and the voluntary sector to deliver whole family, personalised approaches that achieve better outcomes for parents, children and families.



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## Introduction

***“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”***

(Key Principles of Practice for Young Carers and their Families.)

The focus of this paper is on young carers and how personalisation and *whole family* approaches can support them to have the opportunities that other young people enjoy. Partnership working between adult and children’s services is essential in ensuring that young carers are identified and their needs addressed. This paper aims to look in particular at the responsibilities of Adult Social Care within this partnership and to share local experience and learning. It therefore focuses specifically on young carers who care for a disabled<sup>3</sup> adult who, in most instances, will be a parent. It brings together some key practice points along with practical examples to draw upon.

In November 2010, the Coalition Government published *Recognised, valued and supported: Next steps for the Carers Strategy*, its update of the previous administration’s Carers Strategy, setting out its priorities for action over the next four years, focusing on what will have the biggest impact on carers’ lives. The strategy update<sup>4</sup> recognises that many young carers are still not being identified and offered the support they need. It emphasises that effective support for young carers requires adult and children’s services (including health and schools), alongside the voluntary and independent sectors, to work together and prevent young people from taking on harmful caring roles. The strategy update also highlights the benefits of taking a personalised, *whole family* approach, which looks at the needs and views of all individuals within the family. Guidance was published alongside the strategy – *Carers and personalisation: improving outcomes* - that identifies practical approaches to ensuring that personalisation works well for carers.

The government’s Vision for Adult Social Care<sup>5</sup> emphasises the importance of offering personalised support for families and carers and points out that councils should *‘be mindful, when assessing adults, of young carers to make sure they are not being asked to provide inappropriate levels of care’*.

In January 2011 a range of stakeholders signed up to a sector wide commitment to moving forward with personalisation and community based support. *Think Local Act Personal*<sup>6</sup> encourages the active involvement of carers, families and communities in the design, development and delivery of innovative care and support designed to optimise choice and independence.

The approach aims to build on existing strengths, supports *whole family* approaches and underlines the vital connection between information, advice, early intervention and preventative, community- based approaches and personalised care and support. Whilst directed principally at adults the approach is relevant to young carers who take on this role because there are unmet care needs, for whatever reason, within their family.

*Working Together to Support Young Carers – a model local memorandum of understanding [ADASS/ADCS 2009]* sets out how adult and children's services can work together and emphasises the opportunities that personalisation of care brings:

*'The personalisation of care can offer opportunities for innovation and improved responsiveness to the needs of people being cared for. In this context, responses to young carers are not just about social care services but all the services and options available and brought into availability within the local community. This includes access to universal services and local young carer projects. Such an approach requires that young carers and their families are involved in shaping services. We need to respect and recognise young carers' expertise by involving them in the design and building of services. Young carers will have views about what would best help. They should be listened to whilst, at the same time, we ensure they avoid the assumption or continuation of inappropriate caring responsibilities and we fulfill our obligations to provide support to the person cared for to help achieve this.'*

As agreed in the memorandum, this paper uses the term young carer to include *'children and young people under the age of 18 who provide regular and ongoing care and emotional support to a family member who is physically or mental ill, disabled or misuses substances'*. The memorandum recognises the central issues are around those of recognition (including self-identification) adverse impact and support; including emotional support. It adopts the central premise from the Children's Society *Key Principles of Practice* that:

*"...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 her or her emotional or physical wellbeing or educational achievement and life chances."*

There are an estimated 3 million children (23% of all UK children) living in households where there are long term physical or mental health problems, illness or disability<sup>7</sup>. Recent research estimates that 2.6 million children in the UK are living with parents who are drinking hazardously and 705,000 are living with dependent drinkers<sup>8</sup>. Two million children in the UK are estimated to live in households where at least one parent has a mental health problem<sup>9</sup>.

Some of these children provide significant support for an adult either because the adults support needs are unidentified or because they are unmet. Nationally there are an estimated 175,000 'young carers'<sup>10</sup> although a survey published by the BBC in November 2010<sup>11</sup> estimates a much higher figure of 700,000 young people with caring responsibilities. With an estimated 70% of all young carers supporting an adult, the welfare of young carers should be of significant concern to adult social care.

There is a significant body of work that has been done in relation to young carers and whole family approaches. In particular this previous work includes:

- *Whole Family Pathway*<sup>12</sup>
- Key Principles of Practice developed by The Children's Society;<sup>13</sup>
- Learning from the Department of Education Family Pathfinder initiative<sup>14</sup> and the Include Partnership Report of Whole Family development for young carers (The Children's Society and The Princess Royal Trust for Carers)<sup>15</sup>
- The Social Care Institute for Excellence (SCIE) Think Family guidance<sup>16</sup>
- The Local Model Memorandum of Understanding: Working together to Support Young Carers from ADASS and ADCS<sup>17</sup>.

This document draws on much of this previous work and aims to encourage Adult Social Care to learn from and embed the principles from this work in developing strategies, systems and processes for personalisation.

Alongside this paper ADASS and ADCS are publishing a further paper *Signposts 2011* on some of the practical issues surrounding the recognition and support of young carers in families affected by enduring parental mental illness or substance misuse.

## **1. Young carers as experts on their own lives and whole family approaches.**

Personalisation is about developing solutions for people in the context in which they live, in their family and community. Just as every individual is unique, every family is unique and will have its own culture, personalities and history. Good personalised support means meeting individual needs in a way which recognises and promotes each person's immediate family (and community) role/s and network. Understanding individual needs requires an understanding of the whole family and the shared needs and collective assets of the family. Support can then be planned in a way that best meets the needs of the family as a whole, builds on their strengths and prevents children and young people from undertaking inappropriate caring.

Young people have a wealth of knowledge and experience as individuals in their own right, through being an active member of a family unit and through providing or observing support to another family member. If support plans are to be put in place that produce better outcomes for the whole family, the starting point must be that whenever possible there should be communication with *all* children in the family regardless of caring responsibilities. Making this the starting point means that it is more likely that inappropriate levels of caring can be identified and prevented and that parents can be supported to enable their children to achieve their potential and to have the same opportunities that other young people enjoy.

Support arrangements that are personalised around the specific needs of each family are more likely to produce effective outcomes. They can also help prevent young people taking on inappropriate caring roles.

The responsibilities to address the needs of children and young people when undertaking adult care assessment are clearly outlined within guidance on eligibility for adult social care: *Prioritising need in the context of Putting People First*<sup>18</sup>:

*'Councils should identify any children or young people acting in a caring role and consider the impact on them. Community care packages should not rely on the input of an inappropriate level of care from a child or young person. In this respect, in addition to the provision of adult care assessment and support, councils should be prepared to address their duty under the Children Act 1989 to safeguard and promote the welfare of children in their area. The Children Act 1989 also specifies the need to take the views and interests of children into account. In discharging these duties, it is essential that Councils take account of the cumulative effects of responsibilities of family members within the household and where necessary, adult and children's services should work together to protect children from having to undertake unreasonable levels of care.'*

The recent government funded Family Pathfinder Project demonstrates the use of 'family focused' models of support that meet the needs of young people with caring responsibilities and their families. The aim of the project is to provide families with access to personalised, integrated and holistic packages of support that address the underlying factors causing young people to take on inappropriate and/or excessive caring responsibilities. This involves delivering packages of support for the whole family; changing models of delivery for practitioners; increasing awareness of young carers across the authority; and embedding the approach across the whole authority through developing strategic change.<sup>19</sup> Early analysis indicates that developing a *whole family* approach helps identify young carers, provides support that is more personalised, integrated and holistic and can help tackle the causes of inappropriate caring and lift young carers out of these roles.

Children and young people can make positive contributions to the planning and delivery of services at strategic level as well as family unit level. Harnessing the knowledge and creativity of young carers can help to create better communities as well as more effective support plans.

***Key practice points:***

- There are no "wrong doors". Young carers are identified, assessed and their families are supported in ways that prevent inappropriate caring and support parenting roles regardless of which service is contacted first.
- Children are recognised, listened to and communicated with. Staff working with adults introduce themselves and explain who they are to any children who may be present. Children are given age appropriate and relevant information.
- *Whole family* approaches enable the shared needs and collective assets of the family to be considered in planning support.
- Interpreters are used when needed and young carers are not expected to act as interpreters for their parents particularly during assessment and review.
- Approaches support parents to enable them to fulfil their parenting responsibilities
- There is a Memorandum of Understanding between adult and children's services that is understood and acted on by all staff and has senior management support and leadership.

- There is regular joint training between adult and children's services that helps staff in adult services feel they have the skills and permission to talk to children and understand where to signpost young people to if help is needed refer on to
- Young carers and their families participate in shaping the development and delivery of strategy and responses that promote greater choice and control and prevent further inappropriate caring.

***Practical examples and resources:***

**Hampshire Practice Guidance for Adult and Children's Services in supporting Young Carers within a Whole Family Working Model (2011)**

This is a localised, Hampshire document based on 'A Model Memorandum of Understanding' by ADASS and ADCS that aims to support Hampshire in delivering joined-up support around and with the families as a whole, and enhanced partnership working within and between services.

It includes an easy to read flow chart for practitioners.

<http://www3.hants.gov.uk/supporting-young-carers-2011.pdf>

**Social Care TV: Parental mental health and child welfare - a young person's story**

This film is about 18-year-old Cait who has been caring for her Mum since the age of 7. The film explores the importance of involving and assessing the needs of all family members from the outset. It describes Cait's own experience of getting the support she needed and how agencies in Liverpool are working together to improve services for parents with mental health problems and their children.

<http://www.scie.org.uk/socialcaretv/video-player.asp?guid=d9269ac9-4cee-4120-bc72-12dc9383a059>

**Listening to Young Carers.** The Children's Society, in partnership with the Princess Royal Trust for Carers, have supported the development of the first National Young Carers Forum for England. Members of the forum have made a DVD called *Listening to Young Carers*, in which the young people talk about the issues they face and share solutions that will help improve their lives. Available from: The Children's Society [www.youngcarer.com](http://www.youngcarer.com)

**Whole Family Pathway and Key Principles of Practice.** The Children's Society *Include Project*, funded by DCSF, in partnership with The Princess Royal Trust for Carers and Disabled Parents Network have developed a web-based resource on whole family working in relation to young carers for use by professionals and families. It is designed to be used in conjunction with The Children's Society's Key Principles of Practice which provides practice guidance for those working directly with or commissioning services for young carers and their families.

<http://www.youngcarer.com/pdfs/Whole%20Family%20Pathway.pdf>

<http://www.youngcarer.com/showPage.php?file=2010115134320.htm>

**The Milton Keynes Family Group Conference Service** was fully established in 2001. It is a way of working with families where plans and decisions need to be made for children and young people. At a Family Group Conference (FGC) the main people involved are the family and their friends. Families are put in charge of decision making. The agencies will offer information and support. The conference itself may last 2-3 hours. Shared food plays an important part in creating a relaxed atmosphere. The service is funded and managed by Milton Keynes Council but is independent of decision-making and to maintain this independence it has an office based separately from Children's Service's within the Quaker Community Centre.

<http://www.milton-keynes.gov.uk/family-group-conference-service/>

### **Eastern and East Midlands Regional Network of Family Group Conference Services practice standards**

In 2009, the Eastern and East Midlands Regional Network of Family Group Conference Services decided that the increased use locally and nationally of Family Group Conferences required a clear set of practice standards to ensure high quality and effective service provision. These can be accessed at:

[http://www.miltonkeynes.gov.uk/family-group-conference-service/documents/FGC\\_Booklet.pdf](http://www.miltonkeynes.gov.uk/family-group-conference-service/documents/FGC_Booklet.pdf)

**The family pathfinder project in Reading has successfully built strategic links across adult and children's services. This has resulted in changes to how services are planned and delivered in order to provide family focused support.**

In Reading there has been a particular focus on embedding young carer support into mainstream and targeted service provision, rather than operating separate provision, which can run the risk of creating a 'young carer silo'. Joint working and commissioning has also been facilitated by wider whole family working developments at a strategic level.

The creation of a 'Think Family Steering Group' and the active participation of strategic leads from across the LA (such as the Head of Adult Services and the Head of Children's Social Care) has helped overcome barriers to joint working. It also sends the message to other managers and strategic leads that there is an expectation that joint working will take place:

*"Senior buy-in and recognition is necessary. You need a Senior Champion to galvanise support. It's not something that can be driven solely at an operational level."* (Strategic Lead)

## **Think child, think parent, think family**

SCIE has developed a guide to help services improve their response to parents with mental health problems and their families by taking a 'think child, think parent, think family' approach. Since September 2009, five local authority areas and the five Health and Social Care Trust areas in Northern Ireland have been implementing the guide.

An interim report summarizes the findings of the first year of the evaluation of the project. Key messages include:

- Making 'think child, think parent, think family' a reality requires involvement of a range of services
- 'A lot of small changes can make a big difference'
- There are some 'quick wins' – low or no cost actions which can kick start changes.
- The voluntary and community sector have a key role to play, but may need support.
- The Common Assessment Framework and Team Around the Child structures in children's services can provide a good basis for taking a whole-family approach

See full report at: <http://www.scie.org.uk/publications/reports/report44.pdf>

## **SCIE eLearning resources: Parental mental health and families**

E-learning resources have been produced to respond to the training needs for professionals and how to work in partnership, not just between adults and children services, but with families. These E-learning resources are freely available to all. They provide audio, video and interactive technology to assist in exploring the nature of parental mental health and its impact on families. <http://www.scie.org.uk/publications/elearning/parentalmentalhealthandfamilies/index.asp>

## 2. Early intervention and prevention

Identifying young people with caring responsibilities at an early stage is important regardless of eligibility for social care funding and regardless of whether the child or young person chooses to identify themselves by the term 'young carer'. Early identification can help ensure access to the right information, advice and advocacy. Equally important is ensuring that appropriate advice, information and support are provided to the person being cared for and that where appropriate this includes advice and support for their parenting role. This will help prevent children from taking on any inappropriate caring roles and can also help to ensure that young carers are able to have a childhood.

Many children will not identify themselves as carers or tell anyone about their responsibilities. It maybe that they simply see themselves as doing what any son or daughter might do in a family or they may be concerned about the stigma attached by others to the parent's disability, particularly in cases where a parent has a mental health problem or misuses substances. Other young people and their families may not wish to talk about their caring responsibilities for fear of the consequences of intervention from the local authority. A report<sup>20</sup> based on research conducted with a group of black and minority ethnic (BME) young carers and their families found there was not a strong identification amongst respondents with the idea of being a young carer. The stigma attached by others to caring was found to be particularly prevalent amongst BME young people, and even more problematic for boys. The term can also cause problems for parents with some parents feeling that the label 'young carer' implies that they lack parenting skills. It is important that the language used does not become a barrier to communication. Discussing the practical, social and emotional impact of disability on the wider family including talking directly to children and young people in the family can make a major contribution to early intervention and prevention of inappropriate caring roles.

The long term repercussions of caring are identified by one young carer in a report from a young carers workshop by the Commission for Social Care Inspection<sup>21</sup>:

*“People need to recognise that caring for someone costs a lot to you. It can stop you getting on with much of your own life as a child or a young person, it can make it hard to balance what you need to do at school with what you need to do to care at home, and it can make it likely that you will not do well at school. That can make your chances of getting a good job later in life less than they would have been. It can make it hard to get and keep friends. It is stressful and there are risks to your own health. You suffer from the negative way people generally react against people with a disability, like the person you are caring for.”*

Everyone who may come into contact with young carers needs to have a good awareness and understanding of the issues facing young carers and understand what support is available locally for them and their families. Important principles and standards for working with young carers are outlined in *Key Principles of Practice*, guidance for those working with young carers and their families. This includes the following:

*Children who care have 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*

### ***Key practice points***

- There is a programme of activity to raise awareness and understanding of challenges and issues facing young carers and their families. Councils and their partners commit to understand better the issues that get in the way of self-identification by young carers and their families; especially where there are enduring mental health problems or problematic substance misuse.
- The council and partners promote positive images of disabled people and of families living with disability
- Parents are supported in their parenting role effectively and early and there is easily accessible information advice and guidance for parents.
- There is easily accessible support, advocacy and assistance to any young person with caring responsibilities.
- Information, advice and advocacy services are available as part of the wider approaches to "*Think Local, Act Personal*" and empowerment of young carers, families and communities.
- Ensure a multi agency carers strategy includes a focus on young carers in schools

### ***Practical examples and resources:***

**The Gloucestershire Young Carers Forum** 'Our Voice' meets regularly to discuss young carers' issues and has representatives from all of the young carer groups across the county. 'Our Voice' not only plays an important part in decision making processes but also raises awareness about young carers. This year the Forum has been involved in lots of trips, meetings and activities to achieve these goals.

From being interviewed at Gloucester FM radio station; to a trip to the Prime Minister's home; to giving a presentation at the Gloucestershire NHS Annual General Meeting - the Forum members have been very active in getting the message out that young carers do a fantastic job and deserve the best services and support.

<http://www.glosyoungcarers.org.uk/forum/index.htm>

**Recognising young carers: a guide for practitioners.  
The Princess Royal Trust Sunderland Carers Centre.**

This guide aims to raise awareness amongst professionals working with young people and their families of young carers and the issues facing them. It explains who young carers are and the types of 'care' they may be providing, and then explores the potential impact this can have. The guide then looks at how agencies can better support this often invisible and under-served group.

<http://www.sunderlandchildrenstrust.org.uk/content/recognising-young-carers-guide2009.pdf>

**The Princess Royal Trust for carers** has a section of their website dedicated to young carers. It provides information about what it means to be a young carer and how to get the support and information you need.  
<http://www.youngcarers.net>

**Carers Direct** has a section on the website written for and about young people who are caring. It helps you people find out if they are a young carer. It looks at the different things young carers have to do, and where they can get help with them.

<http://www.nhs.uk/CarersDirect/young/young/Pages/Overview.aspx>

**Keeping the Family in Mind resource pack.** 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 by Barnardo's with the participation of young carers. Available from: [www.barnardos.org.uk/resources/research\\_and\\_publications.htm](http://www.barnardos.org.uk/resources/research_and_publications.htm)

**Surrey Young Carers Education Advisers**

Remaining in education can provide challenges for many young people, but for those who have a caring role at home this environment can provide additional problems at times.

Surrey Young Carers Education Advisers are on hand to advise and assist staff to provide listening support, advocacy and information for the students. SYC can assist schools and colleges in supporting their students by providing, as a free service:

- Consultations, briefings within INSET days & staff meetings
- Assembly talks to students
- Setting up Young Carer Groups
- Primary and secondary level PSHE materials

By raising awareness in this way, education professionals are more able to address the issues affecting young carers such as attendance, behaviour, achievement and communication with parents.

<http://www.surrey-youngcarers.org.uk/education/main.html>

### 3. Self directed support and assessment

As adult services transform their business processes to facilitate self directed support and personal budgets, there are real opportunities to ensure that better attention is paid to the needs of young carers and that flexibilities in the use of resources benefit young carers through a *whole family* approach.

*“A whole family approach in assessment, enabling both the individuals who need support and those who will support them to identify their own needs and desired outcomes, is much more likely to result in individual care packages that can be sustained effectively.” (Department for Education, 2010)*

Taking a *whole family* approach to assessment means that the disabled person’s role as a parent forms part of the assessment and the needs and views of children and young people in the household are considered alongside the needs of the disabled person. This will help identify needs in relation to parenting, identify young carers and prevent inappropriate caring responsibilities. It can also help to identify the collective strengths and resources of the family.

Working across agencies and sharing assessments and information will help give a full picture of a family’s needs and help coordinate support. By including questions about young carers as standard in every assessment practitioners can be prompted to think about children and young people in the family.

The *Whole Family Pathway* points out that many Community Care packages rely on the unacknowledged caring role of a child because some agencies that support adults ignore their parenting role. It suggests that when a referral is made for an adult with a disability or illness, the following should be considered:

- Is there a child in the family (including extended family members) who may be helping to provide care?
- What can be offered to help the whole family?
- Does the parent need support in their parenting role?

Routine and coordinated procedures should be established for the early identification of disabled adults with parenting responsibilities, with a view to addressing support needs at an early stage and prevent children caring at inappropriate levels which impact upon their own development and well-being. If needed, consideration should be given to how the Common Assessment Framework might help assess and provide for a young carer.

The responsibilities of adult social care to take children into account when assessing adults with parenting responsibilities are clearly spelt out in policy and guidance. This includes the following from the *Framework for the Assessment of Children in Need and their Families 2000*<sup>22</sup>:

*'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.'*

*Prioritising need in the context of Putting People First: a whole system approach to eligibility for social care - guidance on eligibility criteria for adult social care* published in 2010 also states:

*'In the course of assessing an individual's needs, councils should recognise that adults who have parenting responsibilities for a child under 18 years may require help with these responsibilities.'*

The Coalition Government's *Vision for Adult Social Care* makes it clear that councils should be *'mindful, when assessing adults, of young carers to make sure they are not being asked to provide inappropriate levels of care.'*

Any referral for a child as a "young carer" should trigger an assessment or review of the person in need of support.

**Key practice points:**

- Where services are working with families, the needs of dependent children in the family, including those who may be assisting with caring, are recognized. This means taking account of their hopes, aspirations, strengths and achievements and the need for advice and support for all the family.
- 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. Include the 3 questions:

- Is there a child in the family (including step children, children of partners or extended family) who may be helping to provide care?
  - What is needed to help the whole family?
  - Does the parent need support in their parenting role?
- A joint protocol between adult social care and children's services makes clear where responsibilities for assessment lie and how services work together to assess young carers and the person needing support.
  - Assessments for the young carer and for the adult being supported by them recognise the individual identity of each and their interdependence as family members.
  - Assessments are completed in a timely manner, are age appropriate and specific to the child's needs as a carer.
  - Children and young people are involved in thinking about their needs and their resilience. There is discussion with the young person about any caring role they may be undertaking.
  - Young carers have access to independent information, advice, advocacy and support prior to, during and on completion of assessments.
  - There is a commitment to support and not to undermine parenting capacity and recognition that some families may be fearful of acknowledging young carer roles and that parents and children may have differences of view about appropriateness.

***Practical examples and resources:***

**The Blackburn young carer project** has designed its own whole family assessment, drawing on the 'Framework for the Assessment of Children in Need and their Families' (DoH, 2000). It is a single assessment divided into different sections, each focusing on different members of the family. From this, a Team Around the Family (TAF) meeting is organized and all relevant agencies are invited. Actions and targets are agreed with the family and a Family Action Plan is developed.

Where possible the Family Action Plan is integrated with the care plan implemented by adult services. The Family Action Plan is reviewed every three months.

The Blackburn project has found that the new assessment is prompting support workers to explore families' needs in much greater depth, identifying previously unidentified issues, particularly around parents' needs. In some instances, this has resulted in additional support being provided for families, which has reduced young carers' caring roles.

### **Manual for Measures of Caring Activities and Outcomes**

A number of local authorities working with young carers are using the assessment tools in the *Manual for Measures of Caring Activities and Outcomes For Children and Young People*<sup>23</sup> developed by Stephen Joseph, Fiona Becker, Saul Becker in 2009. These help measure the extent of caring activities that children and young people are involved in, as well as the positive and negative outcomes associated with caring. These tools can be accessed at <http://static.carers.org/files/2248-yc-outcomes-manual-sb-4047.pdf>

### **Kensington and Chelsea Young Carers Joint protocol between Adult Social Care and Family and Children's services**

This joint protocol has been developed to clarify how practitioners from Adult Social Care and Family and Children's services should work together to assess the needs of young carers. The purpose of the protocol is to ensure that there is a shared understanding between professionals so that young carers are identified and their needs met appropriately.

<http://www.rbkc.gov.uk/pdf/Young%20carers%20protocol%20print.pdf>

### **Hampshire's protocol: Safeguarding children and young people whose parents / carers have problems with: mental health, substance misuse, learning disability and emotional or psychological distress.**

This protocol is to safeguard children in families with complex needs and to outline the commitment to collaborative working within and between agencies to meet these needs, it make specific mention to the importance of identifying young carers in these families.

<http://www.4lscb.org.uk/documents/4LSCB%20Procedures/Joint%20working%20protocol%20May%202011.pdf>

## 4. Self directed support and resource allocation

Resource allocation is about deciding the amount of funding to provide for people. Resource allocation systems (RAS) are the systems that councils use to determine the indicative amount of money for the personal budget. In addition to allocating resources to the person in need of support, many councils will allocate additional resources for young carers needs. The amount allocated varies significantly from one locality to another and varies according to individual need, local eligibility criteria and local priorities.

It is important that sufficient resources are allocated to the parent in their personal budget to support them in their parenting role including any needs their children have that may arise from their parent's disability. Department of Health guidance on direct payments (2009) makes it clear that:

*Disabled people who are parents could be assessed as needing services under both community care legislation and/or the 1989 Act to assist them in their parenting role. This means that direct payments can be used to meet the social care needs of them, their children or their family that arise from their disability. It is important that the needs of the disabled person and their family are looked at holistically, bearing in mind that specific duties may arise under particular legislation. In the interest of the family and to avoid duplication, councils should ensure that the assessment process is streamlined and co-ordinated between adult and children's services and other relevant departments.*

Whilst the willingness and ability of a carer to provide support can be taken into account in allocating resources it is important that no reductions in resource allocation should be made on the basis of support provided by carers under 16 and very careful consideration, following a full discussion with the young person concerned, should be given to the level of involvement of carers aged 16-18.

Additional resources can be allocated for the support of a young carer and wherever possible these should be allocated as direct payments to maximize choice and control. Children under 16 cannot receive a direct payment but it can be made to their parent or guardian and this can be helpful in empowering the parent. Where concerns over the management of the money exist, a third party arrangement can be made to hold the money on the parent or young person's (16-18) behalf. Direct payments can be made to young carers over the age of 16 for carers' services if the young person is willing and able to manage these. Research by Carers UK<sup>24</sup> shows that ethnic minority carers are particularly likely to make use of direct payments because they are able to buy more culturally sensitive services.

At the same time, local practice needs to be mindful of the underlying principle that agencies will be working together to ensure, no matter how competent or willing a young carer may appear to be, that all children are protected from undertaking excessive or inappropriate caring roles i.e. where levels of care-giving and responsibility to the person in need of care become excessive or inappropriate for that child, risking impacting on her or her emotional or physical wellbeing or educational achievement and life chances. Resources should be used across agencies in the best way possible to achieve this.

***Key practice points:***

- No reductions in resource allocation should be made on the basis of support provided by carers under 16 and very careful consideration should be given to making any adjustments in relation to the involvement of carers aged 16-18.
- Consideration should be given to allocating resources to disabled people who are parents to assist them in their parenting role.
- Providing an additional allocation for the specific needs of a young carer as a direct payment to the parent can help empower the parent to support their child.
- Young carers over 16 can receive direct payments to support them but this must be consistent with the principle that no care and support arrangement relies on excessive or inappropriate caring by a young carer to make it sustainable.

***Practical examples:***

**In Surrey** funding has been made available for direct payments to support young carers who are under the age of 16. This is for one off direct payments to support the social inclusion of young carers. Payments of up to £500 are available and are administered by Surrey Independent Living Council (SILC). A payment could, for example, be for:

- leisure activities
- holidays
- a computer, software or internet connection to help with the young carer's education

Where the young carer is under 16 years of age, they are not legally able to receive their own carer's direct payment so the payment is made to a responsible adult e.g., a parent or grandparent. Young carers aged 16 or over can receive carer's direct payments in their own right.

**In Liverpool, Barnardos Action With Young Carers** is working with the local authority and health partners to promote a whole family approach to assessment, service planning and delivery across adult and children's services. The following is an example of how they have worked across organisations to encourage a whole family approach to support through the use of direct payments:

Mrs. Ali is a Muslim woman who has physical and mental health problems. She is a lone parent and has a 7 year old son (Noraiz). There are no family members in the area and because of domestic violence, Noraiz's's father is prohibited from having any contact with him. Consideration was being given to prosecuting Mrs. Ali because of Noraiz's high level of absenteeism from school.

A referral was made to Children's Social Care by the Education Welfare Officer because of Noraiz's poor school attendance. Action With Young Carers carried out a full assessment of Noraiz's caring responsibilities and the impact his mum's poor health and support needs were having on him. They made a referral to adult social care for a Community Care assessment for Mrs. Ali. With mum's permission, the young carer's worker attended the Community Care assessment visit and highlighted Noraiz's caring responsibilities, the difficulties Mrs. Ali faced as a disabled parent i.e. ensuring that her son's educational and cultural needs were being met and the impact mum's poor health was having on her son.

Mrs. Ali was provided with direct payments so that she was able to recruit a female PA from her community to support her with her personal, physical and cultural needs and a male PA to assist her to take Noraiz to school and to the mosque. Noraiz's school attendance improved and prosecution plans were dropped.

## 5. Self directed support planning

The introduction of personal budgets for everyone in receipt of social care means that there are opportunities for much greater flexibility, choice and control for families in how they use resources available to them. This should mean that parents and young carers can be better supported and that support plans take a *whole family* approach.

Involving children in the support planning can provide a really useful way of discussing family life and the collective strengths and resilience of the family as well as the best support arrangements. Family group conferences [FGC] can be a useful way of giving families the chance to get together to try and make the best plan possible for the whole family. The principles of FGC are useful to consider in arranging family support planning meetings.<sup>25</sup> Plans should support confident and competent parenting. Parents, whether they are disabled or not, need wherever possible to feel in control, and children need to perceive them as being in control.

Agencies need to work together to ensure that children and young people's needs are addressed and that support planning addresses whole family needs which avoids a silo approach to provision that unintentionally has adverse consequences for another family member. There are specific issues around transition where young carers education, training and employment opportunities become particularly significant alongside issues in relation to income, housing status and emotional, physical health & well being. Young people need to have real choices about the caring roles they take on and opportunities for a life outside caring. Partnership working between adult and children's services, including health, education and housing, is essential to ensure coordinated support at this critical time in a young carers life. Underpinning this should be a sound Memorandum of Understanding between adult and children's services.

No assumptions should be made about families from black and minority ethnic groups (BME) having strong support networks or receiving support from extended families. Research by Barnardo's<sup>26</sup> found that this was not necessarily the case. The needs of young BME carers are similar to other young carers but bullying, social isolation and a need for advocacy may be an increased risk for BME young people.

### **Key practice points:**

- Support planning should promote confident and competent parenting where parents feel in control, and children perceive them as being in control.

- Children and young people affected by disability, particularly those providing support to a disabled parent, should have their views and needs considered, and where appropriate be included in support planning meetings.
- Support planning can be used to bring together individual assessments to provide an overview of family strengths risks relationships and needs.
- No care or support package for a parent or sibling relies on excessive or inappropriate caring by a young carer to make it sustainable
- Support is provided that reduces children's vulnerability to negative outcomes and promotes their resilience
- Support planning includes consideration of how young carers can be helped to achieve their potential; and, to have the same access to education, career choices and broader opportunities as their peers

***Practical examples and resources:***

**Engage Toolkit:** The site brings together information, resources and links to help develop and implement best policy and practice for services to support black and minority ethnic young carers and family.  
[www.engagetoolkit.org.uk](http://www.engagetoolkit.org.uk)

**SCIE social care TV. Linda's story:**

This film follows the story of Linda Rounds, who needs constant care after a car accident. Linda's teenage daughter was looking after her, but this was having a negative impact on the family. Following a visit from a social worker Linda found out she was entitled to direct payments. She used the money to pay her friends to be her personal assistants, helping her to feel comfortable with her carers, and giving her daughter more freedom.  
<http://www.scie.org.uk/socialcaretv/video-player.asp?guid=ee39ff86-6125-45a9-b620-ae3fb10abb4f>

**South Tyneside: Support to suit your family**

**Jackie's story:** Jackie is 44 year old and lives in Jarrow with her young daughter who is 14. Jackie suffers from extreme allergies and has regular asthma attacks. She manages to live her day to day life well however does struggle with her housework. Her daughter Imogen was keeping the house clean and tidy as best as she could until she identified herself as a young carer through a school visit by someone from the young carers centre. A referral to the young carer's social worker for an assessment to take place was made and a support plan agreed that allowed for 2 hrs per week for domestic support.

This enabled Jackie to choose an eco friendly company which used cleaning fluids which wouldn't affect her breathing and equally as important it allowed Imogen to get out and about with her friends instead of carrying out household duties, she also became a member of the Young Carers club which enabled her to mix with children her own age and in a similar position also resulting in her receiving Direct Payments funding to take a trip with the group to Thurston outward bound centre for a 5 day break.

**Kirsty's story:** Kirsty is 30 year old and lives in South Shields with her 4 young children and partner. Kirsty has recently undergone a triple heart bypass. Her partner works full time. She receives good support from her parents but her Mum has recently become ill and is undergoing tests so the support has decreased. Kirsty needed assistance to transport her 2 oldest children to school and then her father is able to pick up. Her eldest daughter was always stressed about arriving at school late. A referral to the young carer's social worker for an assessment to take place was made and support to take the children to school was agreed. She was concerned about receiving the money direct to pay for the escorted transport company as she had financial difficulties so the Direct Payments Team arranged for a managed account company to look after the funds and pay invoices on her behalf. Mum Kirsty said 'This help is greatly appreciated and hopefully as a Mum I will be back taking my children to school myself soon but without this service my family would be under great pressure'

#### **The Coventry Carers' Centre: inclusive, whole-family working**

The Coventry Carers' Centre work with carers from age five upwards, and are therefore able to look holistically at the whole- family situation and help the whole family to deal with the caring situation they find themselves in. There are no artificial boundaries concerning the condition of the person who is being cared for. Many people have a variety of conditions that are allocated to different work streams in health and social care and which can impact on the support that carers receive, too. [www.coventrycarers.org.uk](http://www.coventrycarers.org.uk)

#### **At Action with Young Carers Liverpool, *Message in a Bottle* is a vital part of the support provided for children and young people**

The idea is simple. Each young carer is given a plastic bottle that contains vital emergency information and they keep it in a memorable place – the fridge – until they need it. Hopefully, they never will. Each *Message in a Bottle* contains the phone numbers of key people who can help should a young carer's parent become sick. It also carries medical information on their parent's illness, so the emergency services can act quickly if they are called. And *Message in a Bottle* can prevent children being taken into care needlessly. Each bottle contains details of family or friends who the children can stay with if their mum or dad is hospitalised.

## 6. Self directed support and review

Reviewing the needs of young carers and considering the impact of support arrangements on children in the family should form an important part of the review process. Young carers needs and circumstances change as they develop and these changes alongside other changes in the support needs of the parent need to be reviewed at regular intervals. Reviews should be outcome focused and consider how well the support plan is working for the whole family. It is important to arrange a time when the young carer/s can be present to give their views.

### ***Key practice points:***

- Careful thought is given to who should be involved in the review and how to involve children.
- Review is an opportunity to listen to the views of everyone in the family and see how things are working for each person
- Age appropriate activity is used to involve children
- Reviews provide a valuable means for thinking about desired outcomes; any need to discuss or update them; measure progress towards their achievement; and, any need to refresh support from partner agencies.

### ***Practical example:***

#### **Blackburn**

In Blackburn actions and targets are agreed with the family and a Family Action Plan is developed. Where possible the Family Action Plan is integrated with the care plan implemented by adult services. The Family Action Plan is reviewed every three months

## 7. Developing support opportunities

Personalisation means ensuring that there is a wide range of choice available in support opportunities that are suitable for the unique circumstances of each individual and each family. Joint strategies across children and adult social care should identify how resources can be co-ordinated to provide *whole family* approaches that support young carers within the family. Personalisation can provide effective and flexible services that are responsive to the changing needs of disabled parents so that children do not have to take on inappropriate caring roles and responsibilities in the first place.

Practitioners working in adult social care need to have a good understanding of provision for young carers so that, if required, support can be offered as a shorter term intervention while plans for provision in the family home are implemented. It may not always be specialist young carers' services that provide the answer. It is important that opportunities for young people in general, and mainstream activities that might best suit a particular young person, are not overlooked. The provision of personal budgets can mean that there is much greater scope to develop packages of support that meet the needs of a whole family and commissioners of adult social care should work with commissioners of children's social care to consider ways to achieve this.

As young carers make the transition from children's services to adult services it is important that they continue to benefit from information, advice and support. This can be a particularly challenging time in the life of any young person and young carers may face additional challenges. Targeted specific services that support young carers can be very beneficial in providing safe, quality support to those children who continue to be affected by any caring role within their family. Young carers' projects and other direct services should provide safe environments for children and parents to contact for information and support. They should 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 (*Key Principles of Practice*).

### ***Key practice points:***

- There is partnership working and agreement between adult services and children, youth and education services regarding transition arrangements. This ensures that carers support services include a focus on young carers 18 – 24.
- Adult services promote the flexible use of personal budgets for whole family support.

- Young carers are consulted with and engaged in setting the direction for local commissioning and the development of services and support.
- There is a sound evidence base about the needs of young carers, the choices they would like to make in meeting those needs and how effectively they are achieving the desired outcomes. Gaps in provision are communicated to suppliers and local people.
- There are constructive relationships with providers about young carers' needs and targeted support to help them adapt and respond to achieving agreed outcomes in a way that maximizes choice and control.
- There is a well publicized range of person-centred support for young carers and their families in the local community. These include support solutions that may be found outside of specialist services.
- Universal services are alert to young carers' needs and are responsive and inclusive of young carers. This includes schools, health care, colleges, universities, Job Centre Plus, employers and leisure services providers.

***Practical examples and resources:***

**Worcestershire Young Carers Transition Service 16-24yrs**

The main purpose of this service is to support Young Adult Carers to manage their caring responsibilities during the transition period while receiving information advice and support that will enable them to enjoy a life of their own.

The focus of this service is to minimize the negative impact of caring for Young Adult Carers with regards to their education, training, employment opportunities, their income, housing status and their emotional, physical health & well being.

The Worcestershire Youth Support Service (YSS)- Young Carers Unit and Worcestershire County Council Adult Community Services- Carers Unit have been working in partnership since June 2010 to enable young adult carers to have equal access all the range of carer 'costed' services and any free support provided by Adult Care Services.

Worcestershire is in the process of developing a new service specifically for 16 & 17yrs old young carers to access a carer's direct payment in relation to educational & career opportunities.

## **Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16-24** <sup>27</sup>

This study investigates the experiences, needs and service responses to the 290,000 young adult carers aged 16-24 in the UK today. It provides insights into the diverse experiences and needs of what is a 'hidden' and neglected group of carers. The report includes a series of recommendations for service development for those working with carers aged 16-17, carers aged 18-24 and adult carers and a number of practical examples of emerging service responses to the transition needs of carers aged 16-24.

<http://static.carers.org/files/1738-yac-report-3846.pdf>

### **Westminster young carers service**

Peer support is important for all young people and young carers' services have an important role to play in providing personalised approaches to supporting children and their families. Jason and his family receive support from Westminster young carers service:

Jason is 10 years old and cares for his mother who has mental health illness, she suffers from depression as well as anxiety, and she also suffers from emotionally unstable personality disorder. Jason and his mother live on their own in a busy part of Westminster, where mother's anxieties are heightened every time they have to leave the flat. Jason was seeing his father once a month.

Jason joined the young carer's service and joins in activities there. Jason was quiet, reserved and shy at the beginning, but soon gained confidence and made friends and allegiances with other young carers in his age group. The young carer's service liaises with the mental health team and the school on a regular basis. They also speak to Jason's mother frequently, ensuring that she has a support network in place, which will enable and assist her in caring for Jason. Jason has been supported to have improved contact with his father and his paternal aunts and now takes part in regular family activities and trips with them.

**Family Action** offers a range of services to families and to young carers. This includes working with children and young people on an outreach basis, in their own homes and in the community and activities with parents and children together. Support for parenting for people with learning disabilities is provided through the **Valuing Families** service.

<http://www.family-action.org.uk/section.aspx?id=12>

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- <sup>3</sup> The term 'disabled' is used in this document in a broad and inclusive way as adopted in the Joint Position Statements on Young Carers from The Princess Royal Trust for Carers, The Disabled Parents Network and The Children's Society '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 people included in this definition would identify themselves as disabled people.
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<https://www.education.gov.uk/publications/RSG/AllPublications/Page1/DFE-RR084>

<sup>15</sup> Include Partnership Report of Whole Family development for young carers with 14 Local Authorities (The Children's Society and The Princess Royal Trust for Carers)

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

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## SOME ADDITIONAL RESOURCES

More resources in relation to carers and personalisation can be found at [see also below]:

<http://www.thinklocalactpersonal.org.uk/Browse/Carers/>

See also Department of Health guidance *Carers and personalisation: improving outcomes* at:

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_122076](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122076)

### Some additional Children's Society *Include Project* Resources

Recently published:

*Working with the Whole Family: Developing the vision for young carers, Include Partnership Conference Report 2011 [Is there a URL?]*

<http://www.youngcarer.com/showPage.php?file=201114144421.htm>

In preparation/forthcoming publication:

*Supporting Young Carers and their Families: The Include Partnership 2007-2010*

### More general resources from Think Local, Act Personal [TLAP]

<http://www.thinklocalactpersonal.org.uk/>

This is a sector wide partnership for transforming adult social care. TLAP has launched a number of new resources recently, including:

- *Think Local, Act Personal: Who we are?*
- *Making it Real – marking progress towards personalised, community-based support*; for councils and social care organisations.
- *Personal Budgets: Taking Stock, Moving Forward*; a report summarising research on personal budget delivery, common barriers and advice on how to address them.
- *Adult Social Care Minimum Process Framework, Improving Direct Payment Delivery and Re-thinking Support Planning: Ideas for an Alternative Approach.*
- *National Market Development Forum*: TLAP's provider development work strand and the National Market Development Forum.

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**Your Notes**

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**26 October 2011**

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