



**WORKING TOGETHER TO SUPPORT  
YOUNG CARERS -  
A Model Local Memorandum of Understanding  
between Statutory Directors for  
Children's Services and Adult Social Services**

**7 December 2009**

### **Please Note**

This is a model text for a local joint Memorandum of Understanding between Statutory Directors. The aim is to offer a firm basis for working together and working in partnership with health and third sector partners. The final local text may be varied to reflect local circumstances. Additional areas may be included where this is considered appropriate.

Whilst every attempt has been made to ensure accuracy and promote best practice, the content of this document does not represent a formal statement of the law or Government policy. The Associations cannot accept any responsibility for loss or liability occasioned as a result of people acting or not acting on information contained in this paper.

Nothing in the proposed model joint memorandum of understanding seeks to amend or replace existing statutory or accepted best practice guidance on any of the issues it seeks to cover. Should any conflict or apparent difference in interpretation arise, or if further statutory guidance is issued, the expectation is that the statutory guidance would take precedence.

There is a considerable amount of guidance and best practice material available to guide action. The appendices carry summaries of some of this material and a full list of references and sources used is given at the end. Reference should be made to full copies of the relevant documents as appropriate. Statutory Directors should ensure that further information or legal advice is sought, as necessary, by their Council when making decisions about the introduction and operation of the model joint Memorandum of Understanding.

## CONTENTS

Page

<b>JOINT FOREWORD ADCS and ADASS</b>	<b>5</b>
<b>MODEL MEMORANDUM OF UNDERSTANDING: Young Carers</b>	<b>7</b>
<ul style="list-style-type: none"><li>▪ Joint Statement of Intent</li><li>▪ Key Aims &amp; Outcomes</li><li>▪ “Young Carers” : A shared Understanding</li><li>▪ Having a Multi-Agency Strategy</li><li>▪ Promoting Early Identification</li><li>▪ Assessment</li><li>▪ Safeguarding</li><li>▪ Schools and Young Carers</li><li>▪ Health of Young Carers</li><li>▪ Information, Advice and Advocacy</li><li>▪ Equalities and Diversity</li><li>▪ Language Barriers</li><li>▪ Information Sharing</li><li>▪ Young Carers: Related themes and issues</li><li>▪ Audit and Assurance</li><li>▪ Funding Responsibilities</li><li>▪ Resolving Disagreements</li><li>▪ Commencement, Publication, Variation and Review</li></ul>	
<b>APPENDICES [ Note: not part of the Memorandum]</b>	<b>15</b>
<b>A – Background Introduction</b>	
<ul style="list-style-type: none"><li>▪ Feedback from Young Carers</li><li>▪ Government Guidance</li><li>▪ The National Strategy for Carers [2008]</li><li>▪ Some Recent Initiatives and Evidence</li><li>▪ Working in Partnership</li><li>▪ Taking a Model Memorandum Forward Locally</li><li>▪ Feedback and Reviewing Progress</li></ul>	
<b>B – “Young Carers” – Shared Understandings</b>	<b>18</b>
<ul style="list-style-type: none"><li>▪ Introduction</li><li>▪ Some Current Definitions</li><li>▪ What is “inappropriate”?</li></ul>	
<b>C - Assessing Needs of Young Carers</b>	<b>20</b>
<ul style="list-style-type: none"><li>▪ Introduction</li><li>▪ Statutory Guidance on Assessment of Young Carers</li><li>▪ Assessment Frameworks</li><li>▪ Working together to support Disabled Parents</li><li>▪ Enabling Young Carers and Families to “Have their Say”</li></ul>	

<p><b>D – Young Carers: Safeguarding, Related Themes and Issues</b></p> <ul style="list-style-type: none"> <li>▪ Think Family Initiative</li> <li>▪ Safeguarding Children</li> <li>▪ Schools and Young Carers</li> <li>▪ Health of Young Carers</li> <li>▪ Aiming High</li> <li>▪ Transitions to Adulthood</li> <li>▪ Parents with mental health needs</li> <li>▪ Parents involved in substance misuse</li> <li>▪ Parents with a learning disability</li> <li>▪ Refugee Young Carers</li> <li>▪ Personalisation and Young Carers</li> </ul>	<p><b>24</b></p>
<p><b>E – References and Sources</b></p> <ul style="list-style-type: none"> <li>▪ References</li> <li>▪ Other guidance</li> </ul>	<p><b>31</b></p>

### **Acknowledgements**

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## FOREWORD

Young carers tell us that they value their caring roles and are often proud of the contribution they are able to make in their families. All too often, however, children and young people become carers because someone in their family has significant unmet care needs arising from disabilities, mental health needs or substance misuse. All too often young carers have stepped into the breach, sometimes assuming a level of responsibility that no child should be expected to take on.

In 2001 there were an estimated 175,000 young carers in the UK [1] [17] with around a third caring for a person with a mental illness. It is likely the actual number is higher and research [2] has suggested that around a third of young carers are involved in inappropriate and excessive caring with consequent knock-on effects on schooling and other key areas of their lives.

Children and young people who care have the same rights as all children and young people. In line with ***Every Child Matters*** [3] we should be pursuing the same outcomes for them. They should be able to learn, achieve, develop friendships and enjoy positive, healthy childhoods just like other children.

***Putting People First*** [4] emphasises that care services should be delivered in ways which sustain families, avoids the need to take on inappropriate caring roles and prevents further inappropriate caring. This policy aim, which is also reflected within the 2008 national strategy for carers, is an underpinning principle of the model Memorandum of Understanding. We will do this by working together, across systems and in partnership with health and local carers' organisations and within the resources available, to achieve our goals of ensuring where a parent or another family member has care needs arising from a disability, substance misuse, or mental illness, that:

- there are no “wrong doors” and that 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;
- risks to independence, safety and welfare are responded to in line with ***“Think Family”*** [5] concepts and guidance on ***“Working Together to Safeguard Children”*** [6];
- earlier, better integrated and more effective responses to young carers and their families are available using ***“whole family pathway”*** [7] approaches;
- children are protected from excessive or inappropriate caring roles; further inappropriate caring is prevented; parents feel supported in their parenting role; and, transition to adulthood is supported;
- no care or support package for a parent or sibling relies on excessive or inappropriate caring by a young carer to make it sustainable;
- young carers are helped to achieve their potential; and, to have the same access to education, career choices and broader opportunities as their peers; and,
- there is better recognition and greater participation of young carers and their families in shaping what we do and in the development and delivery of responses that promote greater choice and control and prevent further inappropriate caring.

It is essential, where services are working with families, that we should ensure that the needs of dependent children in the family, including those who may be assisting with caring, are recognised. This means taking account of their hopes, aspirations, strengths and achievements and the need for advice and support for all the family.

We see young carers and families as experts on their own lives. It falls to professionals across all sectors to include them in shaping the personalised responses that best suit their needs within the whole family approach adopted. The approaches and goals we are setting out, however, apply no matter how competent or willing the young carer may appear to be. They apply equally whether care needs arise as a result of mental or physical illness, substance misuse, disability; or whether a parent or a sibling is the focus of support.

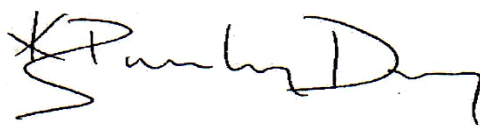
We recognise that progress has been and continues to be made at local level. The purpose of the model Memorandum of Understanding is to provide a framework on which all areas can build. We commend it to all Statutory Directors for consideration. Where it is taken forward locally, we suggest that it is also submitted for endorsement at political management level and that progress is reviewed and reported at intervals.

The model local Memorandum of Understanding offers staff in schools and adults and children's services a clear framework within which they can develop and provide personalised and joined up support for young carers and their families. It is expected that it will apply equally when working in partnership with colleagues in health and the third sectors. Widespread adoption and use of the model Memorandum of Understanding, however, would help us all to build upon our delivery of national policies and local progress so far that promotes:

- achievement of the five key outcomes within “ **Carers at the heart of 21<sup>st</sup> century families and communities**”[1] ;
- personalisation and achievement of the seven key outcomes for social care and the transformation of adult social care inherent in “**Putting People First**”;
- achievement of the five key outcomes in “**Every Child Matters**”;
- delivery of better working with families in line with the three main aims of the “**Think Family**” initiative;
- early identification and intervention in line with the **Healthy Schools Programme** [8] and use of the **Common Assessment Framework [CAF]** [9];
- better joined-up support around and with the family as a whole consistent with **whole family pathway** approach;
- use of supported practice guidance such as the **Key Principles of Practice** [10]; and,
- enhanced partnership working with carers’ organisations, young carers projects, health, local communities and independent sector stakeholders.

This model Memorandum of Understanding is the product of close working with The Children’s Society, carers’ organisations and the ADASS Carers Reference Group. It draws upon material from a range of sources including the experience of local young carers projects. Not least it has been made possible by the invaluable support, advice and assistance from the Department of Health and the Department for Children, Schools and Families.

The ADASS/ADCS Carers’ Reference Group aims to carry out a progress review of the take up and use of the model memorandum towards the end of 2010.



**President  
ADCS**



**President  
ADASS**

Note: references to children include young people.

## MODEL LOCAL MEMORANDUM OF UNDERSTANDING – YOUNG CARERS

### 1. Joint Statement of Intent

The cross government Strategy for Carers launched in 2008 sets out a clear and challenging vision for young carers. It is that:

*“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.”* [p.123]

The vision’s overriding priority is prevention: ensuring young carers are actively protected from excessive or inappropriate caring and parenting roles are supported. This vision has been central to preparing and the anticipated operation of this joint Memorandum of Understanding.

This memorandum builds on the positive joint work that takes place now. It sets out our shared understanding of the issues. This is based on a shared set of aims about how we can deliver better integrated support for families with care needs that ensures better protection from harm and improved outcomes for young carers. It is our joint intention to ensure that all children are better supported not to undertake inappropriate caring by the provision of effective care and support for siblings and parents who need it. We will strive to achieve this within the resources available to us and the national and local policies and priorities that guide us.

### 2. Key Aims and Outcomes

Our main aim is to promote and improve the health and well-being of young carers and their families by preventing and protecting children and young people from undertaking excessive and inappropriate caring roles and responsibilities and preventing the continuation of inappropriate caring. This will be grounded in effective use of supportive practice guidance such as the **Key Principles of Practice** and within the outcome frameworks provided by **Putting People First** and **Every Child Matters**. Where a parent or another family member has care or welfare needs arising from physical or mental illness, substance misuse, or disability we will work together and with our partners in health and carers organisations to ensure that:

- there are no “wrong doors” and that 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;
- risks to independence, safety and welfare are responded to in line with **“Think family”** concepts and guidance on **“Working Together to Safeguard Children”**;
- earlier, better integrated and effective responses to young carers and their families are available using **“whole family pathway”** approaches and during transition to adulthood;
- children are protected from undertaking excessive or inappropriate caring roles; further inappropriate caring is prevented; emotional support is available where needed; and parents feel supported in their parenting role;
- no care or support package for a parent or sibling relies on excessive or inappropriate caring being undertaken by a young carer to make it sustainable;
- young carers are helped to achieve their potential; and, to have the same access to education, career choices and broader opportunities as their peers; and,
- there is better recognition and greater participation of young carers and their families in shaping what we do and in the development and delivery of responses that promote greater choice and control and prevent further inappropriate caring.

### 3. Young Carers: A Shared Understanding

We are agreed that the term “young carer” should be taken to include children and young people under 18 who provide regular and ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances.

The term does not apply to the everyday and occasional help around the home that may often be expected of or given by children in families. The key features for us are that the caring responsibilities persist over time and are important in maintaining the health, safety or day to day well-being of the person cared for and/ or the wider family.

We will continue to work together to develop a shared and more detailed understanding of the different types and levels of caring in our area. Our main focus, however, will be to ensure we develop better ways of identifying where caring by children risks becoming excessive and/or inappropriate and putting in place the support that prevents this happening.

The central issues for us are those of recognition, adverse impact and support, including emotional support. Our 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” [10]*

### 4. Having a Multi-Agency Strategy

We will work together to ensure that, within the overall framework of our Local Strategic Partnership and Children’s Trust, there is a specific multi-agency strategy to meet the needs of young carers. We will ensure this strategy interfaces clearly with both current and future local Children and Young People’s Plans and planning frameworks for Adult Social Care.

The strategy will be developed in collaboration with key partners in health and local support projects for carers and families. It will embrace the views of young carers and their families and reflect the vision that is part of the national strategy. The resulting local strategy will be kept under review and progress shared with local people, young carers, families and partners.

### 5. Promoting Early Identification

It is our shared intention to review local practice and where appropriate to refine it to ensure that it:

- promotes positive images of adults living with long term conditions or disabilities that encourage families to seek information and assistance and identify those children with caring responsibilities;
- provides appropriate and accessible information for families about services that support parenting capacity, independence and well being;
- enables access to self directed support; including direct payments to meet the needs of parents where appropriate;
- reaches out to families to offer support that avoids inappropriate forms of caring developing or continuing;
- reflects principles of partnership working with communities, in particular, the need for sensitivity to cultural needs;
- supports schools in their key role of identifying children with additional support needs and early intervention and support of young carers.
- supports the **National Healthy Schools Programme**; the ability of the local NHS and PCTs in identifying young carers; and ensures that young carers have the same access to health provision, education and career opportunities as their peers;



- recognises the existence of “hard to reach” groups or families and creates opportunities to meet their needs;
- recognises that care needs can vary significantly and that local processes offer emergency advice and support where usual care arrangements risk breaking down; and,
- engages with local young carers’ projects on early support and whole family working.

Support delivered effectively and early for the person requiring care and support that takes account of the needs of dependent children in the family should, in many cases, be sufficient to protect young carers. Almost inevitably, however, there will be some families whose support needs come to light late and when caring by the child is deeply entrenched.

In such cases, it may well be necessary to consider the unmet care or parental support needs of the person cared for and determine what tailored support young carers require immediately and in the longer term, to improve their situation and to reduce the pressures on them.

## 6. Assessment

We are agreed that the key to ensuring better support and outcomes for young carers is effective assessment. As Statutory Directors we will ensure that when a referral is made about a parent with a disability, dependency or illness, agencies consider whether there is a child in the family who is providing personal care or practical help. In doing so, practitioners will also be expected to consider, within a **whole family approach**, the impact of the disability or illness on each child within the family; including whether any of them are or could be providing some form of care or not. We expect action would be taken to assess:

- What additional services may be needed to ensure care needs are met and to prevent a child taking on or continuing to hold inappropriate caring responsibilities.
- Whether the parent needs support in his or her parenting role or in developing parenting capacity.
- What can be offered to help the whole family or to maximise the broader support which others in the family are able to provide.
- Whether the impact on the child indicates that it would be appropriate to undertake an assessment under the **Framework for Assessment of Children in Need and their Families** [11] or under the Carers and Disabled Children Act 2000 [42].
- Whether there are additional needs falling within the **Common Assessment Framework for Children [CAF]** [updated 2009].

We expect appropriate use of the **“Think Family”** toolkit and protocol and, where consistent with the aims of this Memorandum of Understanding, that we embed this and ensure that:

- The primary responsibility for responding to the needs of young carers derives from the person in need of care and support. This means that whichever service identifies there is a young carer in the family, whether it is children’s or adults’ social services or PCT led, is responsible for assessing the needs of that young carer within that family context.
- Practitioners will seek advice and support where necessary from colleagues, whether it is children’s or adults’ social services or a partner agency, to support discharge of our joint and separate responsibilities towards young carers and their families.
- Practitioners will be aware of the prejudices and stereotypes that may exist around cultures, and disability, or about adults who misuse drugs/alcohol or have mental health needs and in terms of their parenting capacity and competence.
- Practitioners will reach their conclusions on the basis of the evidence of their observation of both parents and children; including any young carers.

Joint assessment by adult, child and family and health staff will be expected where this is appropriate. We also expect that relevant staff from local agencies will be available to provide specialist advice and support as needed. Finally, we are clear that staff should never ignore any aspect of a situation that indicates there are concerns about children's safety and they require protection from harm.

## 7. Safeguarding

We accept a joint responsibility to work in partnership with others to identify and respond to any young carers who are suffering, or likely to suffer, significant harm and to protect them from this harm. We will ensure discharge of our responsibilities in ways that focus on working together, early intervention and prevention; reflect practice guidance; do not stigmatize families or risk increasing the number of hidden young carers; and do not discourage young carers and their families from seeking information and advice, or an assessment and provision of services. We will:

- State clearly the responsibilities of staff under local safeguarding children procedures to make referrals where children are considered to be suffering or likely to suffer significant harm and emphasise the principle that safeguarding is everyone's business.
- Ensure staff in all sectors have undertaken appropriate training in recognising harm, reporting concerns about a child's welfare and safety and confirming referrals they have made to children's social care within 48 hours.
- Ensure staff across all sectors have undertaken appropriate training in relation to mental health and substance misuse issues.
- Make sure our arrangements for young carers and their families reflect any requirements of local multi-agency and single agency policies for safeguarding children and seek inclusion as necessary.
- Ensure awareness of safeguarding adults' policy and practice; the ability to recognise and respond to safeguarding adults' concerns; and promote confidence and consistency in using local multi-agency procedures by staff in across all agencies.

## 8. Schools and Young Carers

***Your Child, your schools, our future*** [12] emphasised the importance of early intervention as one of the founding pillars of all schools. The intention is that all children and young people who have additional support needs can be identified early on. Consistent with this and our joint approach, schools will be encouraged and supported to:

- Have a named staff member with lead responsibility for young carers and to recognise this role within continuing professional development.
- Have in place a policy to encourage practice that identifies and supports young carers such as adapting school arrangements if needed, provision for personal tutors and private discussions and access to local young carers' projects.
- Promote open communication with families that supports parenting capacity and encourages the sharing of information.
- Raise awareness about young carers and promote understanding of the caring issues that will touch all families at some point; linking with other agencies as appropriate
- Ensure school policies such as those for enrolment, attendance, bullying, behaviour and keeping safe afford recognition to young carers.
- Ensure Caldicott principles on confidentiality and information sharing are understood and followed.

- Ensure the provision of personalised and effective school-based support that incorporates the principles of awareness, inclusion, understanding and support for young carers to achieve their full potential.
- Incorporate into individual pupil plans recognition and support for the positive aspects of the young carer's role, as well as providing the supports necessary to enable young carers to attend and enjoy school.
- Include positive messages and images about people with disabilities; including, mental ill health within the wider school curriculum.
- Consider and where reasonably practicable take action to remove barriers to physical access and communication and promote inclusion.
- Be sensitive to cultural and religious needs.
- Take advantage of guidance and support in relation to young carers which is available as part of the **21st Century Schools** and **National Healthy Schools Programme**.
- Consider scope for school staff to adopt lead professional roles within the **CAF** process.

## 9. Health of Young Carers

Consistent with our wider responsibilities under the **National Service Framework for Children, Young People and Maternity Services** [13] to develop co-ordinated approaches for all children and young people, in partnership with health, we will explore the scope for more integrated working in relation to young carers that will:

- Promote and sustain healthy cooking, eating and fluid intakes
- Encourage regular exercise and doing about 60 minutes of physical activity each day
- Ensure good oral health
- Raise awareness and reduce risks of substance misuse (alcohol, volatile substances and illicit drugs) and smoking and support young carers interested in giving up.
- Raise awareness of personal stress and how this may be managed
- Highlight the role of doctors and other health professional in identifying or supporting young carers in primary healthcare settings and as part of hospital discharge processes.
- Ensure child and adolescent mental health services support the emotional well being of young carers who are seriously troubled by their caring role
- Provide breaks and activities to enhance mental health and social networks
- Enable young people to assess risks about lifting and handling and provide information, advice and support to remove or reduce risk of injury as necessary.
- Ensure safe procedures exist for the holding and control of medication at all times.

## 10. Information, Advice & Advocacy

Together with our partners, we will work towards a position where, if not already in place, information and advocacy services are available to all young carers and their families offering:

- Information
- Advice
- Advocacy
- Representation
- Support; including peer support through local young carers' projects.

We will encourage local use of the following core principles, which were developed originally by the Department of Health [14], for use when people act as advocates for young carers:

- Advocates should be the young carer's person of choice and can be informal, peer as well as professional advocates.
- Advocates should work for the best interests of the young carer
- Advocates should value and respect young carers as individuals and challenge all types of unlawful discrimination.

- Advocates should work to make sure that young carers understand what is happening to them, can make their views known and, where possible, exercise appropriate choices when decisions are being made.
- Advocates should help young carers to raise issues and concerns about things they are unhappy about. This includes making complaints under the Children Act 1989.
- Advocates should be familiar with requirements regarding the safeguarding of children and know what to do if they become aware of abuse or neglect or risk of it occurring.

As Statutory Directors we accept there are challenges inherent in this commitment. We recognise that from time to time tensions may arise between young carers and those whom they support. We will work to find ways of resolving them. We will commit to meet with young carers not less than once a year to find out what has gone well, what has not and what might make a difference in future.

Opportunities for Elected Member involvement will be identified. We will explore the scope for having a designated Elected Member[s] who would champion the interests and concerns of young carers, and to meet with them at regular intervals consistent with the constitutional arrangements of our Council.

## **11. Equalities & Diversity**

This Memorandum of Understanding applies in all situations irrespective of age, disability, gender, race, cultural or religious beliefs and sexual orientation. It is an underpinning principle within the protocol that, as with abuse or neglect, inappropriate caring responsibilities, cannot be condoned on religious or cultural grounds. We will ensure that appropriate people are readily available to provide advice on such matters.

## **12. Language Barriers**

When considering translation services we will consult with families as to who could fill this role appropriately. Where possible bi-lingual advocates will be used and account taken of any relevant factors around gender or locality. We are agreed it is not good practice to expect young carers to interpret for their families, particularly when it involves someone with an illness and will discourage this. We expect interpreters to be used.

## **13. Information Sharing**

We are agreed that effective and timely information sharing between our own agencies and with our partners is critical to the provision of early intervention and preventative work; to support transitions; and, for safeguarding and promoting the welfare of young carers.

Earlier national guidance on information sharing from 2004 issued as part of *Every Child Matters* was replaced by new cross government guidance in 2008 [15]. Within the framework of existing local information sharing protocols, our aim is to ensure there should be specific recognition of the position of young carers. This will cover their identification and support. Local arrangements for information sharing under this protocol will be consistent with national guidance. We will expect practitioners to follow the seven “golden rules” that are in place:

- Understand Data Protection legislation is not a barrier to sharing information
- Be open and honest
- Seek advice when necessary
- Share with consent where appropriate
- Consider the child’s safety and welfare
- Gather and keep information that is necessary, proportionate, relevant, accurate, timely and secure.
- Keep a record of information shared.

## 14. Young Carers: Related Themes and Issues

There are a number of other issues that may apply to the circumstances of some young carers. We will ensure these inform the need for joint working and shared understandings/processes between adult social care, children's services and partners within health. They are:

- Transitions to adulthood
- Parents with mental health needs
- Parents who misuse substances (alcohol, prescribed or illicit drugs)
- Parents with a learning disability
- Refugee Young Carers

We accept that this listing is not definitive. We will continue to work together on these and other identified issues. Our local arrangements will ensure these and other relevant issues are kept under review and that up to date information is available to all staff. This may include the preparation and dissemination of further information to support joint and separate effective action and good practice in these areas. We will ensure that any additions are consistent with the considerable body of national guidance and best practice materials that are available and which staff are expected to follow.

## 15. Audit and Assurance

We expect the adoption and operation of the memorandum to be consistent with the **Good Governance Standard for Public Services**[16]. To this end, we will put in place arrangements for periodic audit and the provision of reasonable assurance to the Council, partners, young carers, their families and the community on how it works in specific areas or as a whole.

These audit arrangements will be located within wider Council processes for the management of risk and provision of reasonable assurance. The information arising from these audits will be used to inform performance priorities for development and delivery of the key processes and outcomes that the memorandum has been designed to help secure.

## 16. Funding responsibilities

The internal allocations of funding by the Council should not become a barrier to timely and appropriate support. We recognise that disputes about where funding responsibility lies can be deeply damaging to families: they were one of the concerns voiced by families and young carers in the Carers Review national consultations. We will act to ensure that staff have a clear understanding of joint and separate responsibilities to support parenting roles, respond to needs and reduce the need for inappropriate caring by young carers. The following general principles apply to the expected whole family and joint approach to meeting needs:

- Adult social care is responsible for commissioning care and support services for adults to reduce or prevent inappropriate caring responsibilities by young carers.
- Children's social care is responsible for commissioning services to respond to specific needs of the child or young person; including, those relating to the impact of their caring role on them
- Shared responsibility exists between us for commissioning services that would support or sustain adults in their parenting role having regard to the individual circumstances.

## 17. Resolving Disagreements

Young carers have identified that difficulties in adult and children's social care services working together are a source of concern to them and require resolution. We believe that if the holistic, family centred approach we support is to be followed, then significant disagreements between adult and children's services should be the exception.

Almost inevitably, however, there may be occasions when professional staff encounter difficulties in relation to assessment, service provision or funding responsibilities. Two potential areas are:

- Disagreements about whether the need relates to the young carer or the adult or sibling who is supported by him or her; and/or,
- Disagreements about respective responsibilities or thresholds for adults or children.

We intend to reduce the risk of disagreements by:

- ensuring that staff are appropriately trained and supported in understanding and in the exercising of joint and separate responsibilities towards young carers and those whom they support;
- being as clear as we can about our joint and separate responsibilities;
- ensuring young carers and parents have access to information and advocacy services to support them in the exercise of their rights; and,
- ensuring that effective arrangements for consultation, communication and feedback to young carers and those they support are available and acted upon.

There are a number of mechanisms that could be used to resolve disagreements. We have noted the SCIE guidance of 2005 [17]. This suggests the designation of a senior lead for young carers with responsibility to *“...resolve promptly disputes between adults’ and children’s services.”* We accept that how local issues are resolved is a matter for us as the Statutory Directors to determine within the context of our corporate responsibilities within the Council.

The following principles will inform action and decision-making should disputes arise:

- Disagreements about funding responsibilities must not get in the way of responding in a timely manner to situations where it is evident that inappropriate caring responsibilities are being undertaken.
- Disagreements about funding must not be allowed to become a problem for the young carer or the person supported and not be argued about in front of them.
- Disagreements about responsibilities must not leave the needs of family members unmet because they seem to fall between internal administrative boundaries.
- Dispute resolution procedures relating to the joint and separate responsibilities of Statutory Directors for young carers and the people they support will be put in place.
- Statutory Directors have final operational responsibility for ensuring that any disagreements about funding are resolved in a reasoned, timely and appropriate manner with better outcomes for young carers being a primary consideration.

## **18. Commencement, Publication, Variation and Review**

The commencement date for this memorandum of understanding is **xx xxx 2010**. The review date is **31 March 2015** and thereafter every three years or as agreed between us. Variations may be agreed to reflect changing legislative, policy and local requirements and evidence of what works best for young carers.

This document falls within the Council’s Publication Scheme. It will be placed on the Council’s web site and with partners as part of our commitment to work together on these issues.

**Statutory Director  
Children’s Services**

**Statutory Director  
Adult Social Services**

## **YOUNG CARERS**

### **APPENDICES TO SUPPORT LOCAL CONSIDERATION ON ARRANGEMENTS FOR A JOINT MEMORANDUM OF UNDERSTANDING BETWEEN STATUTORY DIRECTORS**

**Please note:** These Appendices do not form part of the model Memorandum of Understanding. Rather, they provide background information that may help when considering its adoption and local application. Please refer to the original source material before making decisions.

## APPENDIX A – BACKGROUND TO THE MODEL MEMORANDUM OF UNDERSTANDING

### A.1 Feedback from Young Carers

As part of the consultation preparatory to the national strategy launched in 2008, young carers and their families raised a number of concerns. They mirrored earlier messages about:

- gaps in the support for the person they care for and the wider family;
- impacts on their own well being, personal development, and education and pressures on their everyday lives;
- lack of recognition by the NHS, PCTs and schools about their needs as children who are also young carers; and,
- the need for closer joint working across adult social care and children's services to ensure better outcomes for children and the person who is supported.

A key message here is that we need to work better together to support young carers and their families to meet these concerns in line with our own professional standards. Young carers were also clear that they expect:

*"... more support for parents to be parents, for family to be a family and for support to give them the time and space they need."*

Lastly, **"They said what?"** [18] offers some useful reminders around the value of whole family approaches. It illustrates the misunderstandings that can arise when the needs of carers and parenting roles are considered in isolation. It confirms the importance of listening to young carers and their parents; understanding how things work within families and meeting needs.

### A.2 Government Guidance

***Practice guidance to the Carers (Equal Opportunities) Act 2004*** [17] suggested that Local Authorities should have *"a protocol, shared between adults and children's services, for identifying and assessing young carers."* A brief review of "protocols" by ADASS last year indicated some local progress but concluded that a national best practice protocol or model memorandum of understanding would help matters move forward more rapidly at local level.

### A.3 The National Carers Strategy [2008] [1]

The cross-government national strategy for carers contains a number of key points relevant to the preparation of a local memorandum of understanding. They are:

- All parts of the system must respond and play a part in service delivery in an integrated and seamless way; including the independent sector.
- A key goal in our mission to improve support for carers must be to ensure that services are also improved for the people being supported.
- We should not see the needs of carers in isolation from those of the people for whom they care.
- Carers have a clearly identified need for personalised, targeted information which will reduce some of the difficulties they face.
- Assessments and support offered should take proper account of the need to protect children from inappropriate caring responsibilities.
- Families and parents themselves should have a greater say in shaping services.
- Currently, the pattern of local support is heavily weighted towards intervention after problems are well established. Better outcomes for young carers will only be secured by moving away from crisis intervention and delivering effective and earlier support to the family and the person cared for.



#### **A.4 Some Recent Initiatives and Evidence**

*The Children's Society* in partnership with *The Princess Royal Trust for Carers and Disabled Parents Network* have produced a template to assist practitioners in understanding and delivering responsibilities for working together [19]. This has been taken up in some local areas. In 2008, with funding support from DCSF, *The Children's Society* also published a paper on **Key Principles of Practice** and an online tool the "**Whole Family Pathway**". Both offer guidance on whole family working and joint local responsibilities for front line practice and policies.

The need for improved joint working was also emphasised in a CSCI report published in February 2009 [20]. This report identified a need to work more closely together, improve assessment and to develop joint protocols to ensure shared understandings of roles and responsibilities. In June 2009 Ofsted reinforced these messages and those of the new national strategy in a short report [21]. This identified that gaps between adults and children's services were a key barrier to improved support and better outcomes for young carers.

There is also evidence to suggest that there are strong links between being a young carer and underachieving at school, with many failing to attain formal qualifications. Nearly 30% of young carers of secondary school age are reported to experience educational difficulties. The proportion is much higher, some 40%, among young carers in families affected by substance misuse and who are particularly vulnerable [1] – p. 48]

Some areas already have joint agreements, strategies or protocols in place. Indeed, this paper builds on this work at local level. Where something is in place now, directors should take the opportunity to review how it is working and consider the scope for material contained in the model memorandum to form part of their local arrangements.

#### **A.5 Working in partnership**

Whilst the model Memorandum of Understanding is between Statutory Directors, achievement of better support and outcomes for young carers and families also requires effective partnership working with schools, health, housing, the third sector, families and local communities. This should include robust and responsive arrangements for working together to ensure the early identification of young carers and timely and personalised responses to their situation.

#### **A.6 Taking a Model Memorandum Forward Locally**

Whilst we commend the model agreement and its principles for local consideration, it remains a matter of local discretion to decide how to translate the content into improving practice and outcomes locally. It is for Statutory Directors to decide how best it fits with current and future local provision, the overall pace of progress in this area and local needs, issues and circumstances. Endorsement at political management level and consultation with stakeholders is also commended to Statutory Directors for consideration.

#### **A.7 Feedback and Reviewing Progress**

Comment and feedback from Statutory Directors and stakeholders would be welcome at any stage. Please send to: [adasscarers@warwickshire.gov.uk](mailto:adasscarers@warwickshire.gov.uk)

**Note:** The ADASS Carers Reference Group and joint carers' leads aim to review progress on the adoption and utility of local memoranda of understanding during the later part of 2010 or the first half of 2011.

## APPENDIX B - “YOUNG CARERS” – SHARED UNDERSTANDINGS

### B.1. Introduction

One of the issues that emerged in preparing the model Memorandum of Understanding was that different definitions or understandings of what is meant by the term “Young Carer” are in place. A straightforward and simple approach to the issue is suggested. At the same time it is recognised that Statutory Directors may wish to test this aspect further. In doing so, the key point has to be that “definitions” should be a means of clarity and not a hindrance to shared understanding and early recognition.

### B.2. Some Current Definitions

There is no legislation that refers directly and specifically to “young carers” as such. The 2008 national strategy [1] does not itself define “young carers”. It does put forward, however, a draft cross government definition of “carers” for discussion. This is supported by examples including one for young carers. There are a number of potential definitions that are available for use. They are:

- First, based on the 1995 Carers (Recognition & Services) Act [22] and used by the Children’s Society and perhaps the safest in terms of use or challenge runs as follows:

*“Children and young people (under 18) who provide or intend to provide a substantial amount of care on a regular basis.”*

- Second, linked to this and referred to by Luke Clements [23], is guidance issued by the former Social Services Inspectorate. This defines a young carer as:

*“a child or young person who is carrying out significant caring tasks and assuming a level of responsibility for another person.”*

- Third, the Social Care Institute for Excellence (SCIE) in **Practice Guide no: 5** uses a definition that comes from earlier work by Becker, Dearden and Aldridge [24] and is:

*“children and young persons under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks.”*

- Fourth, **Blackwell’s Encyclopaedia of Social Work** [Source: youngcarer.com website], which has been used by some councils, defines young carers as follows:

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

- Fifth, a definition included in a draft Children’s Society protocol [19], runs as follows:

*“Young carers are children and young people under 18 who provide, or intend to provide, personal care, assistance or support to another family member on a regular basis. They carry out significant or substantial caring tasks and assume a level of responsibility which is inappropriate to their age.”*

### B.3. What is “inappropriate”?

Many children and young people help out with daily tasks and share in the care of siblings as part of everyday living within their household unit. This is not and should not be an automatic cause for concern. Caring can be a positive and valued experience that strengthens family ties and builds personal skills.

The concern is where caring responsibilities risk becoming too much for the child. Identifying when caring has reached a point where it risks or has become “*inappropriate*” for young carers is principally a matter for assessment of whether the family or young person need more formal support.

Consideration should cover the impact of the tasks and roles being undertaken in relation to the seven dimensions of developmental needs outlined in the ***Framework for the Assessment of Children in Need and their Families*** 2000. In general, if the caring role and responsibilities are having an adverse effect on the young carer’s education or ability to form friendships or undertake social activities and pursuits, this would be an indicator that the situation is inappropriate and an assessment and possible alternative care support is indicated.

This involves having regard to what is done, why, its impact, how often and the extent to which the young person has sole or unsupervised responsibility for an activity which might usually fall to an adult. In making this judgment account needs to be taken of the perspectives of both the young carer and their parent and any tensions between them.

Identifying activities that are “inappropriate” is not always easy. It requires taking account of the expectations, commitment and competence of the children and young people involved. **Key areas for assessment are the emotional pressures and social impacts on young carers in providing support or “looking out” for the person they are concerned to help and in sustaining their family as a family.** The cumulative impact of worrying about or for a parent or siblings can be especially significant where a parent has mental health, substance misuse or other such difficulties and should be recognised.

In approaching the task of assessment, practitioners should be aware of the measures developed to assess the total amount of caring activity undertaken by young carers [25]. Such instruments can help in:

- Identifying young carers
- Contributing to the process of assessment to identify the extent of caring responsibilities and what might help to reduce them
- Examining links with other factors such as age, gender and cultural expectations.
- Identifying the impact.
- Sustaining the family as a unit

In arriving at judgments it is essential that the impact on well being, educational attainment and life chances are kept firmly in mind when the wishes and feelings of the child or young person are ascertained. The overriding responsibility of professionals remains to ensure that the person cared for is receiving sufficient services to manage daily routines such that a young person is not involved in substantial caring responsibilities.

The central issue is one of adverse impact, linked to the central premise set out in the model Memorandum of Understanding 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” [10]*

## APPENDIX C - ASSESSING NEEDS OF YOUNG CARERS

### C.1 Introduction

There is a considerable body of guidance, including toolkits, on assessment. This Appendix tries to offer a very brief reminder of some of the underpinning thinking and requirements that have shaped the construction of the joint memorandum of understanding. Reference should always be made to the full guidance where there is uncertainty or a need for more information.

Young carers are not an homogenous group. They will include those who are the primary carer for an adult and who may assume the main caring role on a regular or episodic basis. In such circumstances, caring roles may embrace emotional support and supervision, as well as or instead of providing physical care and assuming responsibility for managing the home. Young carers may also take on responsibilities for the care of siblings with disabilities or other siblings in need of support where parents, for different reasons, experience difficulties in fulfilling parental responsibilities. Effective assessment is essential if the physical, social and emotional impacts of inappropriate caring roles and responsibilities are to be recognised and managed.

### C.2 Statutory Guidance on Assessment of Young Carers

The statutory guidance on assessment of children in need under the Children Act 1989 and issued in 2000 [11] states:

*“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 difference 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. “*

Whilst, in law, the needs of young carers could be assessed under the Carers (Recognition and Services) Act, 1995, the later statutory **Combined Policy Guidance** [42] of 2005 states:

*“As a matter of law they could be assessed under the 1995 Act but that would not be expected, nor would it be in line with the Children Act 1989 guidance.” [para 10 p.11]*

Under this set of statutory guidance, the expectation is that requirements of legislation relating to carers will be taken into account in assessing the needs of children under the Children Act 1989. Such assessment should embrace all those areas identified in carers’ legislation (i.e. the 1995, 2000 and 2004 Acts) where they are relevant.

Whilst there is potential for a perceived conflict between the two sets of guidance, it might be argued that the later set of guidance supersedes the first. In practical terms, provided the additional responsibilities under the 2004 Act are taken into account the differences may not be considered significant. They should not be allowed, however, to become a barrier or a source of dispute.

Good practice in relation to assessment is, perhaps, best summed up by the following statement on the Princess Royal Trust for Carers web site:

*“A whole family approach to assessment is vital. The community care assessment of the person being cared for should ensure that they do not have to rely on the inappropriate caring responsibility of a child in the first place and should take into account the support they need with their family responsibilities, in accordance with Fair Access to Care guidance.”*

### **C.3 Assessment Frameworks**

The main source of guidance continues to be ***The Framework for the Assessment of Children in Need and their Families***. Initial and core assessments are led by social workers with the involvement of other relevant professionals from both adult and children’s services. Such assessments should be linked where appropriate to an assessment of needs, under adult social care legislation, for any person with parental responsibility where a need for the provision of community care services is indicated.

The ***Common Assessment Framework [CAF]*** is a shared assessment tool for use by any practitioner working with children and their families. It applies where children are identified as having needs in addition to those provided for by universal services but which fall below the threshold for children’s social care. It offers a standardised approach to conducting an holistic assessment of needs designed to assist practitioners to work together to meet them. The CAF can be helpful where there is a need for low intensity or universal services and can help to streamline assessments and avoid duplication. The practitioner guide [2009] [9] confirms that it covers “... *young carers who exhibit additional needs which are as a direct result of their caring responsibilities...*”. Common assessment frameworks, however, are not as yet in place across all of adult social care.

The following principles, aimed at informing local practice, are based on national materials referred to previously and practice points contained within the ***SCIE practice guide 5*** [17], ***Think Family*** (Cabinet Office 2008) [5]; ***Making it Work*** [2002] [26] and the Children’s Society ***Key Principles*** and ***Whole Family Pathway***. The principles offer a basis for consideration and adoption as a means of working together better and more effectively in order to secure improved outcomes for young carers. Local assessment processes are expected to be inclusive and sensitive to cultural perceptions and needs and:

- 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.
- Recognise that some young people have caring responsibilities that are inappropriate and will need support in relation to practical and emotional needs.
- Adopt a common or whole family perspective to understanding of the needs of young carers, that recognises their distinctiveness and interdependence with the person being supported and include:
  - Shared recognition of the role and individual needs and expectations of the young carer within the family situation.
  - An assessment that is completed in a timely manner, is age appropriate and specific to the child’s needs as a carer.

- Consistency and co-ordination of referral and assessment activity to avoid repetition.
  - Access to welfare rights assessments for 16 and 17 year old carers.
  - Use of procedures for reporting child and adult protection concerns.
  - A shared understanding of needs and clarity about expected outcomes or interventions.
  - Provision for separate assessments for the young carer and the adult being supported by them.
  - Differentiation between the needs of the child as a carer and the impact of the supported person's illness or disability on them.
  - A commitment not to undermine parenting capacity
  - Recognition that some families may be fearful of acknowledging young carer roles and that parents and children may have differences of view about appropriateness.
- Ensure that adult services support disabled people in their parenting role and that no care package relies on an inappropriate caring role of a child or young person.
  - Ensure that young carers have access to independent information, advice, advocacy and support prior to, during and on completion of assessments.
  - Promote and use effective information sharing within and between assessment processes consistent with Caldicott information sharing principles, cross-government guidance [15] and duties to improve well being, safeguard and promote the welfare of young carers and the person cared for.
  - Make provision for changing or episodic conditions; including contingency planning for crises should they arise and for people who may not otherwise meet eligibility criteria.
  - Encourage a culture of openness to help identify and respond to needs of young carers and their families.
  - Recognise that young carers and their families are the experts on their own lives and that whilst the welfare of the child is always the first consideration, all children benefit from having well-supported parents.

All assessments should identify the reasons for caring roles, their significance, impact and what needs to change to prevent age inappropriate levels of caring responsibilities being undertaken. Whilst ensuring the identification of individual outcomes, assessments should also have regard to the delivery of the wider outcomes set out in this joint protocol and any local outcomes within multi-agency strategies for young carers.

#### **C.4 Working together to Support Disabled Parents**

***Working together to support disabled parents (SCIE 19)*** [27] helpfully identifies four broad principles surrounding the respective responsibilities of adult and children's social care. They provide the basis for a framework in relation to young carers. They are:

- Adult services have lead responsibility for assessments and care planning when there are no safeguarding concerns and where a parent needs assistance with the routine tasks of looking after children to prevent inappropriate caring roles developing.
- Children's social care have lead responsibility for assessment and planning with specialist input from adult social care where intervention is required to prevent children suffering significant harm or where children's needs are complex; or, where there is a disabled child within the family or where children have taken on inappropriate caring responsibilities.

- Where there are safeguarding concerns about children, Adult social care should be involved and be asked to consider the need for community care services to reduce the impact on the young carers as part of the overall approach to assessment.
- Adults and children's services share joint responsibility to co-ordinate assessments and care planning where parents need support for the medium to long-term to enable them to meet their children's developmental needs and reduce the need for age inappropriate caring responsibilities by children continuing or developing.

Lastly, the point is made that it is essential there is local agreement between statutory directors around funding arrangements so that disputes do not hinder the provision of service to reduce or prevent risk of inappropriate caring roles by children and young people.

### **C.9 Enabling Young Carers to “Have their Say”**

Making a positive contribution is one of the five key outcomes within *Every Child Matters*. The 2009 Young Carers Festival produced the following messages on how adult and children's service can work together better to support young carers and their families:

- Meetings cover “the whole” rather than each “individual”
- Listening to families' needs and meeting them promptly
- Better joined up working and communication
- Actually work together and not as two separate services
- Communicate and feedback to other services about care plans, assessments etc.
- Come to CAFs
- Share information and communication to all involved
- More transitional support (young carers - adult carers)
- Adult Mental Health services need to assess the impact on carers living in the home and to refer to agencies for support.

These messages reflect both the value and the need for a stronger voice for young carers and their families. Similar messages were generated at the Young Carers Festival held in Scotland in 2008. They were:

- The need for secure long-term funding for young carers projects that support them.
- Increased awareness and understanding of young carers and the support they need from school staff, GPs and social workers.
- National recognition of the role young carers together with respect, empowerment and understanding [28].

There is also evidence [29] that the shared experience of young carers through local young carers' projects can assist others in recognising their role. Young carers also have a wealth of experience to contribute to assessment processes, service development and local strategic direction. Two principles emerge:

- All young carers should have the chance to be involved in decisions about their services and be involved in assessment and care planning where appropriate.
- All young carers should have the opportunity and be encouraged to be involved in discussions and decisions about service development, strategic objectives and future plans of local agencies.

## APPENDIX D – YOUNG CARERS: SAFEGUARDING & RELATED THEMES

This Appendix provides some more information on safeguarding and related themes and issues that are relevant to the effective working of the Memorandum of Understanding. The intention is to provide contextual information to support local awareness and discussions on local adoption and application.

### D.1 Think Family Initiative

Following the Government's *Family at Risk Review* a new Government initiative called "**Think Family**" [5] was developed to achieve better outcomes for families at the most risk of poor outcomes. Tested in 15 pathfinder sites, "**Think Family**" approaches are now being rolled out nationally. "**Think Family**" is an integral part of delivering a continuum of services. It will mean looking at systems and support provided to vulnerable children, young people and adults. The aim is to ensure services work together to:

- Identify families at risk of poor outcomes to provide support at the earliest opportunity;
- Meet the full range of needs within each family they are supporting or working with;
- Develop services which can respond effectively to the most challenging families; and,
- Strengthen the ability of family members to provide care and support to each other.

Arrangements for ring-fenced Think Family Grant in 2009/10 are set out in LAC 3112080003. [5] The expectation is that services funded through Think Family Grant should be fully co-ordinated in terms of planning and delivery and with associated funding streams.

### D.2 Safeguarding Children

*Every Child Matters* [3] identified young carers and their families as a group that would benefit from targeted, sensitive help. The first aim of adult and children's social care services should be to ensure that the parent or other family member being supported does not have to rely on the inappropriate caring role of the child no matter how competent or willing the young carers may appear to be.

The key to this is assessment. Where a vulnerable adult has care of a child, adult social care staff should adopt a whole family approach. This includes making an assessment to establish the effect of the parents' ill health or circumstances of the child and a need to "**Think Family**".

Concerns about the welfare of children may need to be considered. In certain circumstances, a parent may have difficulty in maintaining a positive relationship with their children and be in need of support. In other circumstances a young carer may have additional or other needs that require a response in addition to their role as a carer under the Common Assessment Framework. Some may be children in need.

The central issue is whether a child's welfare, health or development might suffer if support is not provided to the child or family. Children's welfare should be promoted and safeguarded by working towards the prevention of any child or young person undertaking inappropriate levels of care and responsibility for any family member.

*Working Together to Safeguard Children*, 2006, [6] recognises, for example, 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 or likelihood of harm in each case. It asks all local safeguarding children boards to take full account of the complexities and challenges of this area of work and requires them to have in place:

- Local safeguarding children 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 or Drug and Alcohol Action Teams and other agencies that can assist in the assessment and outcomes.

It is essential that adult social care staff discuss situations with children's services colleagues in order to clarify concerns and to work in partnership to improve the situation. Equally, it is essential that children's services staff recognise when an adult in a family is experiencing problems that may require intervention to reduce the need for children to act as young carers. This requires that specific arrangements are in place locally to:

- encourage and support recognition and dialogue;
- resolve any issues surrounding thresholds of support; and,
- identify potential third sector and other resources that may help.

### D.3 Schools and Young Carers

As a universal service, schools may well be the first place in which the warning signs of inappropriate caring responsibilities become apparent where young carers are not already known to statutory agencies. Equally, school may be the one place where the young person is able to function outside their caring role and may be a haven for them. Some schools are doing well at identifying and providing support for young carers as shown by The Children's Society ***Include Project*** [30].

It is increasingly clear that pupil performance and individual well being go hand in hand. Over time, inappropriate levels of care will have an impact on a young person's welfare which, in turn, may affect their achievement in school and ultimately their overall life chances.

***Your child, your schools, our future: building a 21 century schools system*** [12] emphasises the importance of partnership working, sharing expertise and providing children with the skills and confidence they need. Tackling problems early is seen as vital for all schools so that all children and young people who have additional support needs can be identified early on and appropriate supports arranged.

### D.4 Health of Young Carers

Staying healthy is one of the key outcomes within "***Every Child Matters***" [6]. The amount and type of care a young carer provides and the impact on health can vary greatly. Physical and emotional well being can vary enormously depending on duration of the caring role and the development of coping mechanisms and support. The length of time a young carer performs an inappropriate caring role is likely to affect how many problems they may have with their health, education, social development and physical or emotional well being: *the caring task is something that never stops*. [10 – p.9]. Young carers may be more at risk of physical problems such as excessive tiredness or as a result of lifting and assisting parents.

Surveys of young carers point to raised risk of stress, anxiety, low self esteem, depression, eating problems, sleeping difficulties and of self harm. These health and well being needs cannot be separated completely from the wider social and economic situation in which young carers live. They point to a need for positive engagement of health partners and effective links into national initiatives. The ***Healthy Schools Programme*** [8] includes a specific project on young carers. Practical guidance outlines how, as part of their healthy schools and broader pupil support work, all schools can take account of the needs of young carers.

## D.5 Aiming High

***Aiming High for Disabled Children*** [2007] [31] builds on the ***Every Child Matters*** programme. The national strategy for carers recognises that its framework has the potential to reduce the need for siblings to take on inappropriate caring roles within the family. It emphasises the importance for children and young people with disabilities of:

- Quality information on options and choices
- Active involvement in transition and making them the centre of positive discussion
- Effective multi-agency working to support the young person
- Focussing on those with the most complex needs and what those needs mean as they move to adulthood

## D.6 Transitions to Adulthood

Young adult carers face all the changes that other teenagers and young people face. Research by the Rowntree Foundation ***“Growing up caring: vulnerability and transition to adulthood, young carers’ experiences*** [32] indicated that many young carers matured quickly and gained practical skills that aided independence. These benefits, however, were “easily outweighed” by decreased educational, social and employment opportunities.

Other studies point to the fact that life changes are often at the forefront of young carers’ minds [33]. As they grow older they will grow out of young carers groups but not the need for support. Specific consideration should be given to joint arrangements for the support for the 18-25 age group to facilitate both the transition to adulthood and to promote independence and well being. A key principle should be that local arrangements for the support of young carers enable them to have the same education and career choices as their peers. Flexible arrangements for information and support during this period are also expected to be in place.

## D.7 Parents with Mental Health Needs

It is estimated that around a third of young carers provide care for someone with a serious mental health problem who is their parent or holds a parental role. Close collaboration and shared information and understandings between adult mental health services and children’s services are essential. Particular challenges can arise in relation to identification and support in these situations. Research indicates that poor mental health of parents may be associated with poor outcomes for their children. Other key messages from research [34] are:

- The unpredictable nature of some mental health problems can create difficulties for young carers whose behaviours are not always correctly attributed.
- The high level of stigma often attached to mental health problems may lead young carers to exclude themselves from social involvement.
- Mothers appear more likely to suffer mental health problems than fathers and support for them is most often given by female children.

It is essential that an appropriate assessment of the parent/carer’s needs is undertaken to assess the impact on children and young carers within the family, its context and its functioning. Children in these situations have the right to have their own needs assessed and to receive appropriate services as children. They should be seen in their own right so that their needs can be identified, protective factors built upon and relevant services provided.

In many cases concerns about young carers or other children in the family arising from the parent’s capacity to meet their children’s needs may be at a level where the issue of actual or potential for significant harm does not arise. If there are concerns, however, about neglect or emotional, physical or sexual harm to a child/young carer then local safeguarding children procedures as outlined above must be followed.

There is other evidence that young carers in these situations may be more at risk of bullying. Parents or young carers may be less willing to seek help because of fears around possible removal of children from home. Schools can play a major role in recognising and responding to the impact of the caring role in these situations. Appropriate onward referral and partnership working are both essential and can make a real difference [35].

## D.8 Parents involved in Substance Misuse

Whilst not all substance misusers' families experience serious difficulties (e.g. recreational users), *Hidden Harm* [36] makes clear that parental problem drug use can and does cause serious harm to children and young people of every age. It makes a number of recommendations relevant to the operation of the memorandum and these should be pursued.

The report recognised that effective treatment for the parent can have major benefits for children. It encouraged working together to take practical steps to protect from harm and improve the health and well being of children who are affected by it. Schools can be a safe haven for the children of problem drug users and may be one of the few places where there is a pattern and structure to their lives. Schools and their staff can do a lot to help children and those with caring responsibilities in these situations.

Local practice should emphasise the need to be supported by and to link effectively with other agencies that offer complementary support, skills and knowledge. The *Include Project* [30] has produced a valuable information paper for teachers and school staff on supporting pupils with substance misusing parents. It offers the reminder that parents and children can hide problems, sometimes very serious ones. Children and young people may be very reluctant to share that they are experiencing difficulties as a result of parental substance misuse (drugs and alcohol) as a result of:

- Feelings of stigma or shame surrounding parental substance misuse;
- Fears on the part of young carers and parents about what may happen when outside agencies get involved;
- Reluctance to seek help or denial or minimisation of difficulties.
- Concerns not to "betray" their parents.

Schools and their partners should work together to identify the impact on individual children and young people and the impacts in turn on their school life. In considering ways forward the views of children and young people on how schools could offer support should be taken into account. Approaches should be sensitive to the fact that parents may be anxious and may worry about losing their children.

Some local safeguarding children boards have developed substance misusing parents and carers' assessment tools [37]. In other areas joint working protocols [38] are in place to safeguard children whose parents/carers use drugs/alcohol or have mental health needs. More recently national guidance on the development of local safeguarding protocols has been put in place. [39] Family Intervention Projects, for example, can help agencies work together more effectively with local alcohol treatment services/drug treatment services. The idea is to jointly develop care plans for parents with substance misuse problems to identify and ensure their children are protected from harm and their welfare needs met. [39]

The principles for assessment outlined earlier in this protocol apply. Successful intervention requires that support for young carers and their families requires that all staff working with them adopt inclusive, wide ranging and holistic approaches centred around:

- The adult or child in need of personal care;
- The child or young person who is caring
- The family

Good practice indicates that all agencies involved in the care or support of substance misusing parents or their children need to work closely together, share information and thoroughly assess situations in a timely and proportionate way to safeguard and promote the welfare of children and young people with caring responsibilities. In particular they have to:

- focus on the child/young carer: consider what life is like for them and from their viewpoint;
- recognise that an adult's management of their own life is a good indicator of their ability to look after the child;
- be aware that the best predictor of future behaviour is past behaviour; and,
- keep in mind information from a variety of sources is better than information from one.

### **D.9 Parents with a Learning Disability**

Joint local approaches to ensure parents access their entitlement to assistance under community care legislation can help reduce the likelihood of parents having to rely on children for assistance. It is understood some councils may have protocols in place already and may wish to build upon them.

Learning disabled parents may need support to develop and sustain their ability to meet the needs of their children. [40] From an early age, children may assume responsibility for looking after or supporting their parents in ways that may be age inappropriate. Their ability to parent may also be compounded by other factors such as poor physical and mental health, unequal access to health services, low incomes, housing difficulties and the availability of strong social networks and extended support.

Adult learning disability services can provide valuable inputs into core assessments of children in need. In general specialist assessments are often needed and joint assessments are commended as good practice.

### **D.10 Refugee Young Carers**

The Children's Society has produced a helpful toolkit [www.refugeetoolkit.org.uk](http://www.refugeetoolkit.org.uk) [7]. This is designed to assist professionals in responding to refugee children who are also young carers. The toolkit offers the valuable reminder that:

*“Fear and lack of knowledge can create barriers to accessing support services resulting in their children taking on unmet care needs for the parents and/or parenting roles for other siblings.”*

When assessing needs and identifying protective and risk factors it is essential that this covers not only the risks faced by a disabled adult but also any risks faced by young carers and other family members if support services are not provided. Key areas to consider are:

- whether children may also care for friends or other members of the community;
- whether children may be caring for more than one person or taking on a parenting role for siblings and other children; and,
- whether an unaccompanied child may also be a young carer.

Cultural concepts of caring and health are not all the same. The concept of a carer may not be understood. How refugees communicate with care professionals may be influenced by their culture and beliefs.

The good practice principles in this protocol apply equally to refugee young carers. Local arrangements made by Directors should also seek to ensure adoption of good practice principles around interpreting:

- recognise the vulnerability of children and young carers acting as informal interpreters and avoid asking them whenever possible; and,
- arrange for trained and consistent interpreters to be available for interviews to improve communication and trust; and,
- ensure children are not asked to interpret for a family member when it relates to health or personal care needs.

Councils may also wish to bear in mind the situation of those young carers who are part of families without public funds.

#### **D.11 Personalisation and Young Carers**

Local action needs to ensure carers are part of the transformation of health and social care as envisaged in ***Putting People First*** and that progress is consistent with any expected milestones [41].

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 carer's 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 fulfil our obligations to provide support to the person cared for to help achieve this.

The Carers and Disabled Children Act 2000 [42] enables local councils to provide carers services and to make direct payments to young carers ***over the age of 16*** for carer services if the young person is willing and able to manage these. The normal local arrangements for resource allocation decisions would apply in these circumstances. The ability to make such payments does not detract in any way from the need to prevent or reduce performance of caring responsibilities. In addition the specific responsibilities continue to apply under the 2004 Act to consider the wish to work or undertake education, training or leisure. Referrals to the *Connexions Service* should be considered where the young carer is aged 13 or older.



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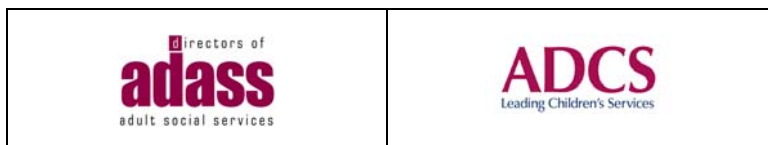
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## YOUR NOTES



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[adasscarers@warwickshire.gov.uk](mailto:adasscarers@warwickshire.gov.uk)