

Commissioning Services for **Young Carers and their Families**

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Acknowledgements

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This resource was funded by The Alan & Babette Sainsbury Charitable Fund.

Carers Trust would like to thank the following staff and peer reviewers who gave their support in the development of this resource:

- Moira Fraser, Director of Policy Carers Trust.
- Pat Faulkner, Network Support Team, Carers Trust.
- Stewart Betts, Service Development Manager (Vulnerable Children and Young People), Norfolk County Council.
- Julie Saggars, Youth Service Co-ordinator, MAAG & Vulnerable Young People, Essex Youth Service.
- Sue Tarling, Carers Commissioner, Commissioning Team, Adult Social Care, Health & Housing, Hillingdon Council.

Published by
Carers Trust
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Carers Trust is a registered charity in England and Wales (1145181) and in Scotland (SC042870). Registered as a company limited by guarantee in England and Wales No. 7697170. Registered office: 32–36 Loman Street, London SE1 0EH.

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Foreword

Over the past decade, there has been growing – and welcome – recognition that ‘care and support’ must be seen as both multi-agency and inter-generational. Historically, young carers were often a silent minority, doubly challenged for being unrecognised as carers but facing major challenges not only within their caring roles but also in fulfilling their own educational potential and preparation for adult life. However, as the 2010 refreshed Carers Strategy acknowledges, young carers form an important strand within the wider carers sector. They want to care, but very often are at risk of inappropriate levels of care which damage their own life chances and often create anxiety and stress across the whole family.

This new resource from Carers Trust is doubly welcome because it offers tools and approaches which will enable commissioners to design and procure services which maximise young carers’ contribution while protecting their own dignity and rights as individual citizens. Very importantly, it reminds commissioners of the importance of adopting a *whole family* focus which reflects and responds to the roles, rights and responsibilities of *all* family members.

As one young carer said to me recently:

‘Caring is not a career choice! It doesn’t happen in isolation and you shouldn’t need to worry about yourself and your family. But you do worry, because sometimes care and support seem like a threat, you worry that they are asking if your mum is a good enough mum and you get scared that they might take you away. Then the teachers, your mates at school, they don’t always understand. Sometimes I feel we [the family] are like a jigsaw. Everyone throws the pieces in the air and tries to make a different picture out of us! We need to change things, talk about care and most of all I want the people out there to see us like a family – not the jigsaw that everyone takes to bits and puts together differently.’

This resource moves beyond the jigsaw approach and offers practical solutions to common problems in commissioning for young carers. It encourages young carers to be seen as strategic partners in planning and offers useful examples of high quality care and support. With escalating demand for care and support across the health and social care sectors, this resource is truly essential reading – solution focused but also providing a vision of what good care looks like for a growing number of young carers and those they support.

Dame Philippa Russell DBE

Chair, Standing Commission on Carers

Introduction and policy context

‘The Government strongly believe that such support should be targeted at those children and families who are most in need, and I encourage local authorities to identify appropriate services for young carers and prioritise them.’¹

Services supporting young carers have evolved over the last decade through mutual learning and refining what works. Many have expanded their provision from solely providing respite activities, to more targeted support and more recently to providing support for the whole family. As the range and targeting of interventions has increased and tools to evaluate outcomes have developed, the evidence base for effective interventions has begun to grow.

However, as the commissioning landscape for health and social care transforms before us and the need for cost effectiveness and value for money becomes even more acute, significant decisions about services for young carers and their families are being made.

The new Health and Wellbeing Boards and Clinical Commissioning Groups, pooled budgets, personalised support, and the shift further towards academies and free schools, offer up huge opportunities for commissioning services for young carers and their families. Since effective commissioning for young carers and their families will straddle not only children’s and adult social care and statutory and voluntary sectors, but also health, education and other areas such as housing, young carers are very much a touchstone for modern commissioning and particularly joint commissioning.

Commissioning services for this group also presents challenges. Young carers may not always be perceived as the most in need group, indeed many may fall below the existing thresholds for social care support. However, if they are not understood or supported appropriately, they are a group who are undoubtedly at real risk of negative impacts on their health and wellbeing, education and social development. Strong and effective commissioning of services is therefore crucial in preventing not only poor individual outcomes, but also inflated costs to the wider public purse.

It is important for commissioners to be as informed as possible therefore, about the needs of young carers, the range of interventions that are being employed and what interventions are working. Commissioners will then be able to make good judgements about services locally that not only address the critical needs of young carers, but are also preventative in nature. To support those who are responsible for these decisions, Carers Trust has developed this resource.

¹ Tim Loughton, Then Parliamentary Under Secretary Of State for Children and Families. Hansard 18 January 18 2011.

Commissioning Services for Young Carers and their Families aims to support commissioners by informing them about the needs of young carers and young adult carers, and their families, and to draw together what has been learned about effectively supporting this vulnerable group. It provides an overview of the key areas for the commissioning of services and offers many practical examples of how services are currently supporting young carers, as well some of the tools presently in use that are proving to be effective.

The vision of the national carers strategy² for young carers is that: ‘Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods’. The Coalition Government’s Positive for Youth approach ‘sets out a shared vision for how all parts of society ... can work together in partnership to support families and improve outcomes for young people, particularly those who are most disadvantaged or vulnerable.’ We hope that this resource will support commissioners, with the resources available, to deliver the best positive outcomes locally for young carers, the people they care for and their families, so that both these visions becomes reality.

Policy framework

Awareness of young carers and the barriers they face has been driving young carers’ issues up the policy agenda. They are now routinely cited as a vulnerable group in health, social care and education settings.

This vision to protect children and young people from inappropriate caring in the National Strategy for Carers, despite there being no definition of ‘inappropriate’, provides a shared point of reference in regard to a young person’s caring role as well as their own individual development.

In 2010, Recognised, Valued and Supported: Next Steps for the Carers Strategy³ ‘refreshed’ the original National Strategy for Carers and advised that supporting carers is in all of our interest. While the vision from the 2008 National Strategy for Carers remains, the Coalition Government identified four priority areas:

- 1 Supporting early self-identification and involvement in local care planning and individual care planning.
- 2 Enabling carers to fulfil their educational and employment potential.
- 3 Personalised support for carers and those receiving care.
- 4 Supporting carers to remain healthy.

² Department of Health (2008), ‘Carers at the Heart of 21st Century Families and Communities, A caring System on Your Side. A Life of Your Own.’ HM Government.

³ Department of Health (2010), ‘Recognised, Valued and Supported: Next Steps for the Carers Strategy’. HM Government.

The National Strategy for Carers is underpinned by a range of national policy and guidance identifying young carers as a group of young people needing support and highlighting the important role of adult social care in ensuring that parents and families are supported and young people are not required to take on inappropriate caring roles.

For example: 'The importance of the young carer obligation under the 1995 Act⁴ stems in part from the failure of some adult services departments to identify and properly support this group. The 1995 Act obliges adult services to ensure that children and young people looking after an adult are not left with unreasonable caring responsibilities in the first place.'⁵

Furthermore, Putting People First: a Shared Vision and Commitment to the Transformation of Adult Social Care⁶ highlights a need for a personalised Adult Social Care System, which will have: 'Agreed and shared outcomes which should ensure people, irrespective of illness or disability, are supported to ... sustain a family unit which avoids children being required to take on inappropriate caring roles.'

There are clear pointers to the role of local authorities in minimising caring roles for young people through provision of adequate support for adults. Prioritising Need in the Context of Putting People First (2010)⁷ states that: '25. 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. (Emphasis added).

26. 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.'

As well as highlighting the crucial role of adult social care, guidance also underlines the importance of children's and adult services working together.

⁴ Carers (Recognition and Services) Act 1995.

⁵ Clements, L (2011), 'Carers and their Rights the Law Relating to Carers Fourth Edition'. Carers UK.

⁶ Ministers, local government, NHS, social care, professional and regulatory organisations (2007), 'Putting People First: a Shared Vision and Commitment to the Transformation of Adult Social Care'. HM Government.

⁷ Department of Health (2010), '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'. Department of Health.

Working Together To Support Young Carers and their Families a Template for a Local Memorandum of Understanding⁸ is intended to promote working together between adult and children's social care services and offer an enhanced basis for working in partnership with health and third sector partners. It acts as a template so that the final local text can reflect local circumstances.

The Memorandum of Understanding is also clear that identification of 'inappropriate' caring is a matter for assessment. Indeed, young carers do have the right to an assessment. The binding Policy Guidance to the Children Act 1989 (the Framework for the Assessment of Children in Need and their Families)⁹ states: '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.'

Current good practice points to the importance of assessing the needs of young carers in relation to the needs of the whole family. This is highlighted in The Framework for the Assessment of Children in Need and their Families (2000)¹⁰ which states that: 'An assessment of family circumstances is essential.'

At the time of writing, changes to both adult and children's social care and health legislation are imminent which are likely to affect young carers.

⁸ Association of Directors of Adult Social Services (ADASS), The Children's Society and Association of Directors of Children's Services (ADCS) (2012), 'Working Together to Support Young Carers and their Families: A Template for a Local Memorandum of Understanding [MoU] between Statutory Directors for Children's Services and Adult Social Services'. ADASS and ADCS.

⁹ Department of Health, Department for Education and Employment, Home Office (2000), 'Framework for the Assessment of Children in Need and their Families'. The Stationery Office.

¹⁰ Department of Health, Department for Education and Employment, Home Office (2000), 'Framework for the Assessment of Children in Need and their Families'. The Stationery Office.

About Carers Trust

Carers Trust is a new charity formed by the merger of The Princess Royal Trust for Carers and Crossroads Care.

Carers Trust is the UK's largest charity for carers. With local Network Partners we work to improve support, services and recognition for carers in communities across the UK. We offer practical help, both in and outside the home, desperately needed breaks, information and advice. Together with Network Partners we work as one organisation united by a shared vision for carers.

Our vision is of a world where the role and contribution of unpaid carers is recognised and they have access to the quality support and services they need to live their own lives.

Together with Network Partners we reach almost half a million carers a year, including more than 24,000 young carers.

We provide 24-hour access to information, advice and peer support at Carers.org. Our website YCNet offers dedicated support for carers aged 18 and under.

With Network Partners we develop and share high quality and innovative services for carers.

Our unique network enables us to drive policy change, based on direct knowledge of carers' needs at UK-wide, nationwide and local level.

We regularly work in partnership with other organisations for the benefit of carers, for example our project with the Royal College of General Practitioners is helping GPs to identify carers before they reach crisis point.

Using this resource

This resource is structured around the Understand, Plan, Do and Review phases of the commissioning cycle.

The following resources from Carers Trust will also complement this resource:

- Drawing together some of the practice that is already taking place across the country, Carers Trust is showcasing a diverse range of new, established and innovative practice that will support all who commission or develop services for young carers and their families. See <http://professionals.carers.org>.
- The Carers' Hub is a project by Carers Trust which showcases interventions for adult and young carers and is a ready-made evidence base from which to draw. See www.carershub.org.

Chapter 1: Understand: Understanding local needs and involving young carers, families and services

This section aims to:

- Provide key facts about young carers and young adult carers.
- Give an overview of the needs of young carers and families from a national perspective.
- Offer ideas of how to better understand the needs, resources and priorities of local areas through engagement of young carers, their families and services for young carers.

Young carers – key facts

There are many definitions for a young carer including the following:

‘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.’^{11 12}

This definition is contextualised by stating that: ‘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 and is part of community and family cohesion.’

Also, 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 wellbeing or educational achievement and life chances.’¹³

¹¹ Association of Directors of Adult Social Services (ADASS), The Children’s Society and Association of Directors of Children’s Services (ADCS) (2012), ‘Working Together to Support Young Carers and their Families: A Template for a Local Memorandum of Understanding [MoU] between Statutory Directors for Children’s Services and Adult Social Services’. ADASS and ADCS.

¹² Note: This definition does not include many young adult carers (16–24) who are also addressed in this guidance.

¹³ Frank, J, Mclarnon J (2008), ‘Young Carers, Parents and their Families: Key Principles of Practice – Supportive Guidance for those who Work Directly With, or Commission Services for, Young Carers and their Families’. The Children’s Society.

The range and scale of caring varies greatly. It can involve lots of physical care including personal care, giving medication and helping someone to dress or move around. It can be looking after siblings, paying bills, cooking, cleaning, shopping or translating. Some young carers give no physical care but provide emotional support, particularly for someone who has a mental health condition or misuses substances.

Young carers are eligible for assessment under carers legislation and the Children Act 1989 as children 'in need'. However, only a minority of young carers are receiving a formal assessment. 'Those caring for someone with drug/alcohol problems are more likely to receive an assessment under the Children Act.'¹⁴

Key statistics include:

Young carers

- There are 175,000 young carers (under 18 years) in the UK.¹⁵
- 13,000 of the UK's young carers care for over 50 hours a week.¹⁶
- Following a survey in 2010, the BBC estimated that there are 700,000 young carers in the UK.¹⁷
- 22% of young people under 16 in the UK (2.6 million) live with a hazardous drinker.¹⁸
- In the UK, 335,000 children live with a drug dependent parent.¹⁹
- 50% of young carers care for ten hours or fewer per week; one third for 11–20 hours per week; and 16% for over 20 hours per week. 2% care for more than 50 hours each week.²⁰

¹⁴ Dearden, C, Becker, S (2004), 'Young Carers in the UK: the 2004 Report'. Carers UK and The Children's Society.

¹⁵ UK Census 2001. Source: Office for National Statistics licensed under the Open Government Licence v.1.0.

¹⁶ UK Census 2001. Source: Office for National Statistics licensed under the Open Government Licence v.1.0.

¹⁷ The BBC, with assistance from The Princess Royal Trust for Carers, surveyed 4,029 pupils in ten secondary schools and found 337 had caring responsibilities.

¹⁸ New estimates of the number of children living with substance misusing parents: results from UK national household surveys, National Addiction Centre and Criminal Justice Research Centre, BMC Public Health 2009, 9:377, 8 October 2009.

¹⁹ New estimates of the number of children living with substance misusing parents: results from UK national household surveys, National Addiction Centre and Criminal Justice Research Centre, BMC Public Health 2009, 9:377, 8 October 2009.

²⁰ Dearden, C, Becker, S (2004), 'Young Carers in the UK: the 2004 Report'. Carers UK and The Children's Society.

- 68% of young carers are bullied in schools and having a caring responsibility is one of the main characteristics of young people aged between 14 and 16 who have been bullied.²¹
- Over 39% of young carers had not informed their teacher or any member of staff that they were a young carer.²²
- 27% of young carers (aged 11–15) miss school or experience educational difficulties (40% where children care for a relative with drug or alcohol problems).²³

Young adult carers

- Young adult carers aged between 16 and 18 years are twice as likely to be not in education, employment, or training (NEET).²⁴
- In total there are 290,369 carers in the UK who are aged 16–24.²⁵
- There are 61,051 young carers aged 16–17 in the UK.²⁶
- There are 229,318 young adult carers aged 18–24 in the UK.²⁷
- As young people grow older they become more heavily involved in caring and there are differences between young men and women among the 16–28 age group in relation to domestic tasks and intimate care. 85% of young women are doing domestic tasks compared to 68% of young men, while one third of young women in this age range are providing intimate care compared to 17% of young men.²⁸

²¹ Supporting young carers – A School Resource Survey. The Princess Royal Trust for Carers survey 2009. Characteristics of bullying victims in schools DFE 2010.

²² Characteristics of bullying victims in schools DFE 2010.

²³ Dearden, C, Becker, S (2004), 'Young Carers in the UK: the 2004 Report'. Carers UK and The Children's Society.

²⁴ Audit Commission (2010), 'Against the Odds'. Audit Commission.

²⁵ UK Census 2001. Source: Office for National Statistics licensed under the Open Government Licence v.1.0.

²⁶ Becker, F, Becker, S (2008), 'Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16–24'. The Princess Royal Trust for Carers (secondary analysis of UK Census 2001).

²⁷ Becker, F, Becker, S (2008), 'Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16–24'. The Princess Royal Trust for Carers (secondary analysis of UK Census 2001).

²⁸ Becker, F, Becker, S (2008), 'Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16–24'. The Princess Royal Trust for Carers (secondary analysis of UK Census 2001).

The needs of young carers and families

‘Young carers and their families are experts on their own lives and as such must be fully informed and involved in the development and delivery of support services.’²⁹

For over a decade there has been considerable consultation of the needs of young carers and their families. This has driven practice locally and informed national practice. The messages have been very consistent.

Young carers tell us that they want:

- More help for the person they care for.
- To choose the level of caring they do and to get breaks.
- To not feel so worried and guilty.
- An education, an independent future and a career.
- To do the fun things that other young people do.
- Understanding and flexibility.
- Continuity in key worker support.

While parents tell us they want:

- Quality support to look after their children, before and beyond the point of crisis.
- More understanding, less discrimination.
- Parent support groups.
- Child-centred provision (for example, for hospital visits).
- Freedom from fear of removal.
- Continuity in key worker support.

The primary message from young carers has consistently been the need for more support for the person they care for. A second point of note is the need cited by both young carers and their parents to have the continuity of a key worker.

²⁹ Frank, J, McLarnon J (2008), ‘Young carers, Parents and their Families: Key Principles of Practice – Supportive Guidance for Those who Work Directly with, or Commission Services for, Young Carers and their Families’. The Children’s Society.

Furthermore, young carers have consistently stated the value of the direct support they receive from a local young carers service: 'Young carers speak particularly highly of the project-based support they receive. Many value the social and support activities projects provide and the opportunity they offer to get a break and mix with other young carers.'³⁰

'All (young carers) agreed that what was needed was more of the same sort of support they got from young carers groups. The young carers were clear they need help that fitted their individual situation ... what they didn't want was a lot of new ideas and projects – they said it was a problem that when there was some money people always seemed to want to do something new and different, which was never as good. In short, do more of what already works, and 'don't keep coming up with new stuff'.³¹

The national picture – what young carers services say

Although it is vital to understand local needs, it is important to note that young carers services across the UK share very consistent messages in what they believe should be strategic priorities.

In its response to the Government during the refresh of A National Strategy for Carers, The National Young Carers Coalition (NYCC) identified five key priorities submitted by its member networks. The majority of services represented by the NYCC supported the following priorities:

- 1 Early identification and prevention of young carers.
- 2 Adoption of the ADCS/ADASS Memorandum of Understanding.³²
- 3 Outreach to hidden young carers.
- 4 Awareness-raising.
- 5 Support for young adult carers.

³⁰ Department of Health (2008), 'Carers at the Heart of 21st Century Families and Communities, A caring System on Your Side. A Life of Your Own'. HM Government.

³¹ CSCI (2006), 'Being a Young Carer: Views from a Young Carers' Workshop'. CSCI.

³² Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) (2009), 'Working Together To Support Young Carers – A Model Local Memorandum of Understanding between Statutory Directors for Children's Services and Adult Social Services'. ADASS and ADCS.

Understanding the needs, resources and priorities in a local area

‘A good strategic needs assessment, which many areas are already doing, is based on a joint analysis of current and predicted health and well-being outcomes, an account of what people in the local community want from their services (those provided by the statutory sector and the wider market) and a view of the future, predicting and anticipating potential new or unmet need.’³³

A good local understanding of the current and likely future needs of young carers is crucial in developing a strategy that will meet those needs and that is economically efficient and effective.

The National Strategy for Carers states that: “Councils and their strategic partners should routinely involve carers in their Joint Strategic Needs Assessment (JSNA) and development of local carers strategies to ensure that the needs of carers of all ages within the local population, including carers within ethnic minority communities, are adequately reflected.”³⁴

The ‘Understand’ phase should therefore involve assessing the views of young carers and their families in the local area, in order to design and deliver services that most appropriately meet their needs with the resources that are available. Of course, some young carers and families don’t want to be consulted, but many will be keen if there are appropriate mechanisms in place.

Being mindful of any local Compact agreement, it will also be important to involve local young carers services and other services that support families, since they will have information, expertise and insight to contribute, as well as being a conduit to young carers and families themselves.

Many areas will already have benefitted from having developed a local young carers strategy, normally steered by a multi-agency young carers steering group. Since the strategy should have already included thorough consultation and local assessment of need, it would therefore be valuable to incorporate knowledge and learning that has evolved from it into the needs assessment.

³³ Department of Health (2007), ‘Commissioning Framework for Health and Well-being’. Department of Health.

³⁴ Department of Health (2010), ‘Recognised, Valued and Supported: Next Steps for the Carers Strategy’. HM Government.

Involving young carers in the planning process

'The Government urges relevant bodies in every area to involve young people in making decisions about council, health, transport, and other relevant services.'³⁵

For services to be truly carer-led, young carers and their families need to be able to make decisions about services that affect them. It is therefore crucial that both are involved in an area's needs assessment as well as other phases of the commissioning cycle.

Involving young carers and families in planning, designing and improving services makes sense and is more likely to lead to real, long-lasting and sustainable change with better outcomes. Young carers know what would make their lives better and are the experts when it comes to their needs and their caring roles. Involving young carers can also provide feedback about services that commissioners might not get by any other means as well as highlighting any gaps in service provision.

Apart from their obvious knowledge about their own needs, young carers are very often best placed, next to the person they care for, to talk about the needs of service users and should therefore also be involved in the planning and commissioning of those services.

Some of the most effective examples of young people's participation involve young people being given the opportunities to learn about local democracy, how councils operate and how to represent the views of their peers. An evaluation of approaches to commissioning young people's services³⁶ highlights the benefit of holding focus groups with young people to identify services needed in a local area. In some areas young people have been trained on aspects of commissioning (with some gaining accreditation for this),³⁷ and have subsequently been actively involved in commissioning services, including designing tender specifications and forming separate interview panels in the latter stages of the tendering process.

Barriers to involvement by young carers

Because of their caring role, young carers may have difficulty in getting involved in participative and consultative events. Consideration should therefore be given to repeating events and using a menu approach so that young carers can select which events they engage with. The use of technology such as social networking, online surveys, chatrooms and other mechanisms can further maximise the participation of a wide range of young carers and help engage those who may find it difficult to participate in events after school or on the weekend.

³⁵ HM Government (2011), 'Positive for Youth Executive Summary'. Department for Education.

³⁶ Ofsted (2011), 'An Evaluation of Approaches to Commissioning Young People's Services'. Ofsted.

³⁷ Young Devon has created an accredited training programme to enable young people to participate meaningfully in the commissioning of services. See www.youngdevon.org.

It is also important to remember that many young carers are not identified and are therefore not known or supported by current service provision. These young carers, especially those from hard to reach groups, are precisely those who an improved commissioned service should be aiming to support. In order to hear what these young people are saying about their needs and current services, commissioners will need to take both a proactive and creative approach and seek to gather views from young people through other routes such as schools, youth services, health and social care settings.

Engaging with young carers' services and other services that support young carers and their families

Involvement of local people will be supported by the local Healthwatch membership on the local Health and Wellbeing Board, however, assessing the needs of young carers may be difficult and as highlighted, their needs are many and varied.

Engaging with young carers services and other voluntary sector services can therefore be highly valuable in engaging young carers. Young carers services are already engaged with many young people and their families who may not be known to other services and working with them should lead to a more time and cost effective consultation exercise, representing good value for money. A service where young carers are already engaged should be able to offer the advocacy, opportunity and methodology required to support young carers to ensure their voice is heard. Many young carers services already have an established forum or council of young people who act as champions and as a mouthpiece to represent the views for their group. Others such as Blackpool Carers' Centre have established the post of a Young Carers Champion.

Norfolk Young Carers Forum – commissioning involvement

'The Forum's involvement in the commissioning process has been especially valuable, helping to ensure that our specifications truly reflect the views of young carers, and contributing to a tender-evaluation process in which service users have real influence. Forum members always approach these processes with maturity and commitment, earning the respect of all of us who have worked alongside them.'

**Service Development Manager (Vulnerable children and young people),
Norfolk County Council**

Norfolk County Council was keen to ensure the meaningful involvement of young carers in the commissioning process. A consultation exercise with the Young Carers Forum, through discussion and workshop-style exercises explored what the outcomes for the local area should be. Opinions were also sought on what knowledge and resources future service providers should have. The information fed directly into the service specification that was developed by Norfolk County Council. Importantly, the Council reported back to the Forum how their ideas had been incorporated into the specifications, as well as explaining why some ideas were not included.

Apart from engaging young carers and their families with the consultation process, young carers services will have much expertise and local knowledge themselves. They are likely to have information on the different groups of young carers in the local area and other relevant local specific needs.

With commitment at senior level it should be possible to:

- Recognise young carer participation as ‘core business’ and allocate a budget and other sufficient resources, including staff time to do it effectively.
- Inform and educate people about the importance of participation.
- Use local carers organisations, such as Carers Trust Network Partners, to help.
- Include young carers who may face stigma or are harder to reach, such as black, Asian or ethnic minority (BAME) carers, gay and lesbian carers and carers of people with alcohol and substance misuse issues.
- Provide all the information that young carers need to participate on an equal footing with others and make all information clear and jargon free.
- Develop feedback mechanisms to ensure young carer input makes a difference to service delivery.
- Develop tools to evaluate the effectiveness and impact of young carer participation, what works and what doesn’t and what barriers exist.³⁸

Kensington and Chelsea’s needs assessment and young carers strategy

The Royal Borough of Kensington and Chelsea carried out a needs assessment to establish how well services were meeting the needs of young carers and to highlight where provision could be improved. The information provided the basis for the strategic priorities in its young carers strategy.³⁹ For each of these priorities, the strategy sets out clearly what young carers had said in the needs analysis.

Service mapping included:

- Mapping the range of universal services.
- Analysing the current provision against the recommended provision set out in The (former) Princess Royal Trust for Carers guidance, Delivering Every Child Matters for Young Carers.⁴⁰

³⁸ <http://professionals.carers.org> accessed October 2012.

³⁹ The Royal Borough of Kensington and Chelsea (2009), ‘Kensington and Chelsea’s first Young Carers’ Strategy 2009 to 2013 ‘Supporting children and young people that care for parents’.

⁴⁰ The Princess Royal Trust for Carers (2006), Delivering Every Child Matters for Young Carers. The Princess Royal Trust for Carers.

- An audit exercise with a range of professionals across adult health and social care services, children's health, education, social care services, and the community sector. Using a number of young carer case studies, professionals were asked to identify what possible services the young carer and their families should be offered to ensure the best possible outcomes.

The results of the full needs assessment and a full breakdown of the profile of young carers were presented in an evidence document that accompanied the strategy.

What would be the impact if current or proposed services did not exist?

Having considered the benefits and outcomes of local service provision for young carers and their families, it is useful to analyse what the impact might be without such provision. If young carers were not identified and supported, consider the impact on the following:

- Crisis and safeguarding work.
- Young carers' mental health, isolation, school attendance and bullying.
- Young carers becoming NEET.
- Referrals of young carers and families to health, social care or other services.
- The number of preventative referrals to wider services (for example, to parenting support, which would impact on subsequent services).
- The increased need for support from other agencies due to stress on families.
- The local workforce development with respect to young carers.

Further reading and resources

See information about the Blackpool Carers' Centre Young Carers Champion at <http://professionals.carers.org>.

The NYCF, with The (former) Princess Royal Trust for Carers and The Children's Society, has developed the following, all available on www.youngcarer.com:

- A **guide** and **poster** for setting up and running a young carers forum.
- **Listening to Young Carers (DVD)**.
- **Messages to professionals from The NYCF**.

For an example of how a local authority has engaged young carers in the commissioning process see <http://professionals.carers.org>.

How to Involve Children and Young People in Commissioning: Participation Works, provides an introduction to commissioning and describes ways that you can support children and young people to participate in all aspects of commissioning. See www.participationworks.org.uk.

The Engagement Cycle is a free resource supporting commissioners to understand and engage with patients, carers and the public in decisions made about health service provision. See www.institute.nhs.uk.

Chapter 2: Plan: Designing services that meet young carers needs

This section aims to:

- Offer a starting point for a vision to underpin local planning.
- Detail what constitutes recognised good practice for supporting young carers and their families and highlight a number of approaches for service provision.

A local vision

A good local commissioning plan, built on the learning from the JSNA and on the agreed priorities in a Joint Health and Wellbeing Strategy, requires a good vision to underpin it. The original vision for A National Strategy for Carers⁴¹ is a laudable one: ‘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)’. Brackets added.

The following priorities that are set out in Recognised, Valued and Supported: Next Steps for the Carers Strategy,⁴² develop that vision for all carers:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.
- Enabling those with caring responsibilities to fulfil their educational and employment potential.
- Personalised support both for carers and those they support, enabling them to have a family and community life.
- Supporting carers to remain mentally and physically well.

These outcomes, which came out of considerable consultation with young carers and service providers, present a good starting point. However, it is important to ensure that both the vision and the priorities that underpin a local plan are indeed local and reflect the learning from the ‘Understand’ phase of the commissioning process.

⁴¹ Department of Health (2008), ‘Carers at the Heart of 21st Century Families and Communities, A caring System on Your Side. A Life of Your Own.’ HM Government.

⁴² Department of Health (2010), ‘Recognised, Valued and Supported: Next Steps for the Carers Strategy’, HM Government.

The impact of being a young carer can be wide ranging and their needs as well as the needs of their family are often manifold and diverse, spanning health, children's and adult social care, education and housing, as well as for some, mental health and substance misuse services. Often, financial and transport needs will also form part of the mix.

For this reason, it is vital for children's and adult services, health and the voluntary sector to work closely together. The adoption of a local protocol for joint working will be important in achieving this. Working Together To Support Young Carers And Their Families: A Template for a Local Memorandum of Understanding⁴³ was therefore developed as a basis for local authorities to develop their own local versions that reflect local circumstances.

Services need to be commissioned that develop the local area as a whole, are truly integrated and that respond specifically to the needs of young carers and families, as well as building the capacity of other services, including universal services.

The level of caring responsibility for young carers will lie on a wide spectrum, but will for many, due to the nature of the condition of those they care for, move significantly in either direction along that spectrum. The area as a whole therefore needs to reflect this and be able to respond flexibly to the diverse and changing levels of need experienced by young carers and their families.

Hard to reach groups

While all young carers should be able to experience the outcomes of A National Strategy for Carers, some groups and communities will have particular needs as a young carer or experience specific barriers to accessing support. These groups will be identified through strong local needs assessments, but may include:

- BAME communities.
- Refugee and asylum seeker carers.
- Travellers.
- Younger carers (aged 5–10 years).
- Young adult carers (aged 16–24 years).
- Young carers from rural areas who may experience increased isolation due to lack of transport and service provision.
- Children caring because of parental mental illness, substance misuse and other stigmatised condition such as HIV.
- Young carers who have offended or are at risk of offending.

⁴³ Association of Directors of Adult Social Services (ADASS), The Children's Society and Association of Directors of Children's Services (ADCS) (2012), 'Working Together to Support Young Carers and their Families: A Template for a Local Memorandum of Understanding [MoU] between Statutory Directors for Children's Services and Adult Social Services'. ADASS and ADCS.

- Young carers with special educational needs and disabilities.
- Sibling carers, although not a hard to reach group, form a significant group who can often go unnoticed or unsupported.

Age appropriate

It is vital that consultation, support and information provision is adapted for young carers from different age groups.

Further reading and resources about hard to reach groups

- SCIE. 'Think Child, Think Parent, Think Family: a Guide to Parental Mental Health and Child Welfare'. See www.scie.org.uk.
- Barnardo's. 'Keeping the Family in Mind (a resource pack)'. See www.barnardos.org.uk.
- Association of Directors of Adult Social Services and Association of Directors of Children's Services. 'Signposts, See Me, Hear Me, Talk to Me – Talk to my Family as Well, Working Together to Improve Outcomes for Young Carers in Families Affected by Enduring Parental Mental Illness or Substance Misuse'. See www.adcs.org.uk.
- The Children's Society. 'Supporting Young Carers in Families with HIV, Information for HIV Professionals'. See www.youngcarer.com.
- The Children's Society. 'Supporting Refugee Young Carers and their Families – A toolkit for all Practitioners'. See www.refugeetoolkit.org.uk.

Good practice in supporting young carers and their families

The iterative process of local practice informing national guidance has evolved clear approaches to good practice that are recognised across the sector as vital for supporting young carers and their families. Effective commissioning for young carers and their families should include:

- a. A whole family approach.
- b. Targeted support for young carers and families.
- c. Early intervention and prevention.
- d. Supporting access to education, employment and training.
- e. Improving access to transport for young carers.
- f. Improving and maintaining the health and wellbeing of young carers.
- g. Transition support: seamless support from young to adult carer.
- h. Personalisation: individual budgets and direct payments.
- i. Workforce development and raising public awareness.
- j. Giving young carers a voice.

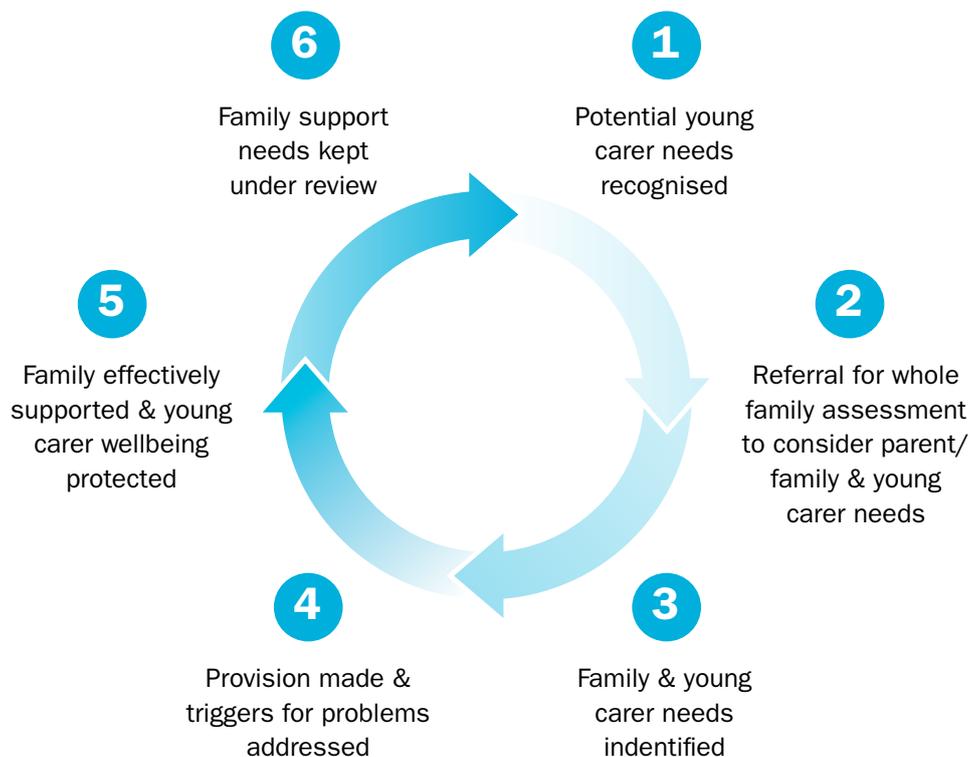
a. A whole family approach

‘I would like an assessment for each person in need in our family.’

Parent

There have been significant developments over the last few years around a whole family approach to supporting young carers and their families and how this approach, can significantly help to reduce inappropriate caring roles.

The diagram⁴⁴ below outlining this approach contrasts with a narrower approach where the sole focus is on the respite needs of young carers. Important as this is, unlike the whole family approach, the focus is not on affecting the unmet needs in a family and therefore is unlikely to reduce the burden of caring on a young carer.



What constitutes a whole family approach?

There are a number of different components that can be commissioned that will support the development of a whole family approach. These include:

- Whole family assessments.

⁴⁴ Department for Education (2010) 'Think Family Toolkits, Improving Support for Families at Risk, Guidance Note 9: Improving Support for Young Carers'. Department for Education, protected by Crown copyright.

- Support for adults and other family members within the family, such as parenting support and provision of practical and emotional support.
- Building support networks including engaging the wider family through for example, family group conferences.
- Relationship building within the family, such as support with building roles, routines and responsibilities and engaging families in positive activities (for example, planning a menu, cooking together or a family picnic).

The key worker

The use of a key worker has been shown to be valuable in helping to coordinate and deliver a whole family approach and has proved a useful role for initiating and undertaking assessments, drawing up support plans and supporting and advocating for families. Having a single consistent point of contact facilitates the development of trust and engagement of families and a key worker has been found to be vital in ‘achieving improved and sustainable outcomes for families’.⁴⁵

Integrated working

Where services are working in an integrated fashion and strong joint working is in place, wider support for the whole family can more easily be drawn in from both the statutory and voluntary sector. In particular, where there are strong joint working arrangements between children’s and adult services, this facilitates the provision of additional help for adults within the family, to support them with substance misuse or mental health issues, for example.

Team Around the Family approaches have been used effectively to coordinate an integrated approach to meeting the needs of families. Building on the Team Around the Child approach and the Common Assessment Framework (CAF) model, it can draw in a wide range of support from both the statutory and voluntary sector.

While this approach is common in children’s services, commissioners should also look to working across adult services to ensure that a whole family approach is delivered and that adult services also initiate, coordinate and engage with the Team Around the Family approach.

Other joint working initiatives are forging seemingly successful models of practice and delivering positive outcomes for families. Appendix A outlines the successes of partnerships between voluntary sector young carers services and services for families. Similarly, further models of partnership working between the voluntary and statutory sectors are being developed through the Carers Trust Integrated Interventions Programme, part of the Building the Evidence, Building the Practice project, funded by the Department for Education in 2011–13. Findings from this work can be found at <http://professionals.carers.org>.

⁴⁵ York Consulting (2011), ‘Turning Around the Lives of Families with Multiple Problems – an Evaluation of the Family and Young Carer Pathfinders Programme’. Department for Education.

Whole family assessments

Prioritising Need in the Context of Putting People First⁴⁶ emphasises the duty on the local authority to provide support which sustains families so as to avoid 'children being required to take on inappropriate caring roles'. It also advises that: 'Community care packages should not rely on the input of an inappropriate level of care from a child or young person,' and that in discharging their duties, 'it is essential that Councils take account of the cumulative effects of responsibilities of family members within the household'.

The use of a whole family assessment to determine the individual and interrelated needs of family members has taken various forms, including using assessment tools developed by young carers services, building on and incorporating the CAF, or using an information gathering model.

The young carers service in Blackburn with Darwen⁴⁷ used a whole family assessment to underpin whole family support for the family as part of the Young Carers Extended Pathfinder. See <http://professionals.carers.org>.

Action for Children Services Ltd (Birmingham Young Carers), in partnership with Birmingham City Council, is piloting a project that is targeting young carers in families with multiple problems. This project is working intensively with young carers and their families to coordinate the assessment, intervention and review of service delivery through the multi-agency family CAF. This project is linking into the city's CAF team and uses the referral pathway already in place and which is already widely promoted. Carers Trust will be publishing an evaluation of this in 2013.

One tool that is now widely used across the sector is The Manual for Measures of Caring Activities and Outcomes for Children and Young People⁴⁸ which contains a range of tools relevant for assessment and evaluation work with young carers.

⁴⁶ Department of Health (2010), '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'. Department of Health.

⁴⁷ Child Action Northwest Young Carers Service in Partnership with Blackburn with Darwen Borough Council.

⁴⁸ Joseph, S, Becker, F, Becker, S (2012), 'The Manual for Measures of Caring Activities and Outcomes for Children and Young People.' Carers Trust.

Further reading and resources about whole family working

- An example of whole family working from Crossroads Care Norfolk Young Carers Project. See <http://professionals.carers.org>.
- The Children's Society Include Project. 'Whole Family Pathway.' See www.youngcarer.com.
- Kendall S, Rodger J, Palmer, H. 'The Use of Whole Family Assessment to Identify the Needs of Families with Multiple Problems.' Department for Education. See www.education.gov.uk.
- The Children's Society, Include Project. 'Prevention through Partnership Programme'. See www.youngcarer.com.

b. Targeted support for young carers and families

'The research consistently reports positive feedback from young carers about young carers projects. In this setting many young carers consider their problems and experiences to be valued, understood and recognised. They prefer support that is non-intrusive and provided by individuals and organisations other than statutory services.'⁴⁹

Targeted support for young carers and families was one of the outcomes of A National Strategy for Carers and the value of a young carers service cannot be underestimated. Young carers and families have consistently stated how they value their local young carers service, where staff are available who understand their distinct needs as young carers and where they are given the chance to meet peers in similar situations to their own and who are therefore understanding and non-judgemental.

Most young carers services offer a combination of both practical and emotional support to young carers and many have now adopted a whole family approach. Young carers services are already likely to be delivering many of the interventions suggested in Appendix C in their local area, often doing so in partnership with other local voluntary or statutory services.

Instead of simply signposting or referring on, many young carers services are now responding increasingly to the needs of the whole family by directly supporting families and by actively coordinating the support of other services. This approach is very much valued by families who welcome having a link or key worker rather than having to negotiate with lots of other agencies. It also means that young carers services are more able to facilitate a reduction in inappropriate caring roles by ensuring that services (both statutory and voluntary) are put in place for the person with care needs who is therefore less reliant on the young person to provide care.

⁴⁹ SCIE (2005), 'Research Briefing 11: The Health and Well-being of Young Carers'. SCIE.

Young carers services provide a level of expertise and focus in supporting young carers that universal services, by virtue of being universal, cannot provide. Many are able to be flexible and creative in how they deliver services.

By championing the needs of young carers and families, many local services have also driven forward strategic change and workforce development in local areas.

Not all young carers however, will wish to access a targeted support service and some will simply want access to mainstream activities.

c. Early intervention and prevention

Putting People First⁵⁰ contains a commitment that local areas will have a ‘Sustainable Community Strategy, utilising all relevant community resources, especially the voluntary sector, so that prevention, early intervention and enablement become the norm’.

Indeed, evidence promotes the importance of addressing underlying issues in order to bring about effective outcomes rather than later intervention when problems have become entrenched (for example, Narrowing the Gap Report.)⁵¹ For young carers and their families this is particularly true.

Historically, many young carers have struggled on in their caring roles without ever being identified and now despite improved awareness and support, it is often acknowledged that still only a minority of young carers actually receive support. It is vital that young carers are not left to cope, unknown to agencies, with potentially increasing levels of care, which over time can lead to a range of negative outcomes including poor educational achievement and damage to their health and wellbeing.

Instead, it is important that local areas put in place mechanisms that facilitate early identification and support for families and young carers. Many different services are potentially involved in providing early prevention and/or intervention for these families and signposting them to specialist services.

Evidence suggests that both universal and targeted services are important in early intervention.⁵²

⁵⁰ Ministers, local government, NHS, social care, professional and regulatory organisations (2007), ‘Putting People First: a Shared Vision and Commitment to the Transformation of Adult Social Care’. Department of Health.

⁵¹ Local Government Association (2008a), ‘Narrowing the Gap: First Report, What Research is Telling us – A Review of Literature and Evidence by NFER (a summary)’ Centre for Excellence and Outcomes in Children and Young People’s Services.

⁵² C4EO (2010), ‘Early Intervention and Prevention in the Context of Integrated Services: Evidence from C4EO and Narrowing the Gap Reviews’.

For young carers and their families this should include:

- i Systems to facilitate early identification and self-referral.
- ii Accurate information and information sharing.
- iii Strong assessments of the needs of a family (including future risk factors).
- iv Integrated support.
- v Targeted support to build the resilience of young carers and families.
- vi Identification and support within schools.

i. Systems to facilitate early identification and self-referral

To create an environment that engenders early identification and self-referral it will be important that:

- All frontline staff in both children's and adult services, health and education and other agencies such as housing, are trained to be aware of the signs that someone is a young carer and what support they can provide in their role.
- There is clear, age-appropriate information that can be easily accessed by young people and families at the right time.
- Local areas ensure there are appropriate systems and opportunities for families and young carers to self-refer.
- Local partners such as libraries and pharmacies provide information and signpost to support.
- There is a local 'visible and transparent offer' of support for young carers and their families.

To support areas to develop a 'transparent offer' that will inform professionals, families and young people how an area supports young carers, Carers Trust, in partnership with The Children's Society, has developed the resource Local Authority Young Carers Website Portal, which gives recommendations for web content that sets out how a local authority supports young carers and families. See www.youngcarer.com.

Norfolk County Council produces an annual handbook for all carers that sets out how and where carers, including young carers, can get support. See www.norfolkcarershelpline.org.uk.

ii. Accurate information and information sharing

‘One of the key principles underpinning early identification is the need for accurate information on the groups most likely to be in need of help (see LGA 2008b; Dyson et al 2010). This entails comprehensive, timely data and sophisticated analyses to inform services.’⁵³

Often areas do not have a sophisticated picture of their young carers, and the numbers supported are frequently much lower than the actual number of young carers in that area. Similarly, it is not uncommon for schools to be unaware that they may have pupils who are young carers and local intelligence on school attendance and attainment of young carers is only beginning to surface.

In Oxfordshire, the local authority collected data on the attainment and school attendance of pupils with caring responsibilities in order to understand more about this group and in order to assess what their needs were in terms of service delivery. See <http://professionals.carers.org> for the details and findings of this data collection which clearly showed an educational attainment gap for young carers.

iii. Strong assessments of the needs of a family (including future risk factors)

To ensure early intervention, all agencies and staff that support adults should recognise the impact of the parent’s illness or disability on their children. They should be alert to the needs of young people who have, or are at risk of having, caring responsibilities and ensure that their assessment procedures include some quick and simple questions:

- 1 Do you have children?
- 2 How does your health problem affect them?
- 3 How can we support you in your role as a parent?
- 4 What support do other members of your family need?

Importantly, when a young carer is being assessed, the key question should be whether the person they are caring for is receiving services that meet their needs and an assessment of their needs should be triggered at this point.

As previously highlighted however, a whole family approach to assessment is the key.

⁵³ C4EO (2010), ‘Early Intervention and Prevention in the Context of Integrated Services: Evidence from C4EO and Narrowing the Gap Reviews’.

iv. Integrated support

Integrated support that is underpinned by clear protocols and referral pathways is essential in ensuring early intervention and prevention, through effective signposting and referrals across all agencies in health, social care, education, housing and others.

v. Targeted support to build the resilience of young carers and families

Family circumstances and caring responsibilities for many young carers can be extremely variable. It is better to support young carers through early intervention rather than allowing them to struggle later on, if and when their circumstances become more difficult. Even for young carers and families who are coping reasonably well and where caring responsibilities appear limited, ensuring low-level support is often crucial in order to keep the situation stable and sustainable.

Young carers and families who have already accessed low-level support, developed trust and confidence in a service, learned skills and formed supportive relationships, are likely to be more resilient and more able to seek and engage with further support at an early point than if they had not. Early targeted support can also set in place crisis or emergency plans which may help mitigate negative impacts if the situation should deteriorate.

vi. Schools

Schools are one universal service which can play a significant role in the early identification and support of young carers. Historically, pupils with caring responsibilities were only identified after their attendance or behaviour had dropped. However, by having a policy and framework of support for young carers and by working in partnership with other agencies and professionals such as school nurses, schools will be able to identify young carers earlier and implement preventative support.

In addition to improved personal outcomes for young carers and families, early intervention and prevention of escalating caring roles will secure cost benefits through the prevention of more costly future services. A good example of this is the much improved identification and support within schools that is occurring in some areas. Compare this to when young carers were often only identified at the point where their attendance had dropped dramatically and the involvement of the Education Welfare Service was required.

d. Supporting access to education, employment and training

‘Finally admitting to my teacher what was going on at home was the bravest thing I’d ever done ... after that, things finally changed for me.’

Young carer

The previous section highlighted the vital role that schools can play in the identification, early intervention and support of young carers. Some schools do this through strong partnership work with a local young carers service.

Awareness of young carers in schools and colleges has increased dramatically over the last decade and some schools have developed excellent mechanisms for both identifying and supporting this vulnerable pupil group.

Unfortunately, many schools are still dismissive of the possibility that they might have pupils who are young carers. Research by the BBC in 2010 however pointed to a figure of 700,000 young carers in the UK and found approximately 8% of secondary school pupils interviewed had caring responsibilities. It is therefore likely that all schools will have some pupils who have caring responsibilities. It is also quite likely that a school will not know who these pupils are. Historically, many young carers have struggled through their education anonymously and without support. A survey by The former Princess Royal Trust for Carers found over 39% of young carers surveyed were not known to be carers by school staff and 68% said they had been bullied in school.

Previous research showed 27% of young carers aged 11–15 experience educational difficulties or miss school, rising to 40% where children are caring for a relative with substance misuse or alcohol issues.⁵⁴ Being a young carer can seriously affect a pupil's attendance, achievement and attainment at school, and many young carers report that they have dropped out of school in the past.⁵⁵ Often however, schools are unaware that caring responsibilities are the root cause.

Despite much anecdotal evidence, strong evidence for this is scant, however as already highlighted, Oxfordshire County Council found clear evidence of the impact of being a young carer on school attendance and attainment.

Having caring responsibilities can also seriously affect a pupil's future wellbeing and life chances. Problems often continue on into adulthood and many young adult carers have difficulties accessing further/higher education, employment or training. A report by the Audit Commission,⁵⁶ found that just over 40% of young carers had been NEET, for over six months or longer. It was also found that the likelihood of young carers being NEET for six months or more was twice that of their peers.⁵⁷ Ofsted has also highlighted young carers as a group who are more likely to fall into the NEET category.⁵⁸

Research by York University estimates an average lifetime public finance cost of £56,301 for a young person who is NEET aged 16–18. However, costs for young carers are likely to be higher.⁵⁹

⁵⁴ Dearden, C, Becker, S (2004), 'Young Carers in the UK: the 2004 Report'. Carers UK and The Children's Society.

⁵⁵ For more information on young carers and education refer to the young carers/ education section at www.carers.org/professionals.

⁵⁶ Audit Commission (2010), 'Against The Odds, Targeted Briefing – Young Carers'. Audit Commission.

⁵⁷ Audit Commission (2010), 'Against the Odds Re-engaging Young People in Education, Employment or Training'. Local Government.

⁵⁸ Ofsted (2010), 'Reducing the Numbers of Young People not in Education, Employment or Training: What Works and Why'. Ofsted.

⁵⁹ Audit Commission (2010), 'Against The Odds, Targeted Briefing – Young Carers'. Audit Commission.

To counter these personal and financial impacts, local areas must ensure that young carers are kept engaged and the barriers to their education are lowered. Furthermore, young adult carers should be supported to progress into further study, training or the workplace.

Supporting young carers need not be something that schools do on their own. Schools can benefit from involving a range of local agencies to provide support. In many areas there are young carers services that can work with schools to deliver support such as:

- A weekly school peer support group.
- One-to-one support for young carers.
- Personal, social, health and economics education lessons, citizenship lessons or assemblies on young carers' issues.
- Training for all staff and governors.
- A young carers peer mentoring or buddying scheme.
- Additional curriculum support or homework clubs.
- Information detailing support.

It is important for schools to link with a range of agencies and professionals to ensure that additional support is provided to the family with the aim of reducing a pupil's caring responsibilities.

By implementing a policy for supporting young carers and appointing a designated member of staff with responsibility for them, support can become properly embedded. Indeed both these were cited as good practice by Ofsted back in 2009.⁶⁰

The Pupil Premium offers schools the opportunity to support young carers in a targeted way through building their own capacity and through partnership working with external agencies.

Carers Trust has written Pupil Premium: Support for Young Carers⁶¹ that highlights how support for young carers through the Pupil Premium is low cost, cost effective and targeted at an appropriate pupil group. See www.carers.org.

For those young carers who are struggling to achieve their full educational potential at school, it is also worth considering how youth services can support young carers. Accreditation schemes, such as ASDAN short course awards and Youth Achievement Awards are a good way of supporting some young carers at risk of becoming NEET.

Commissioners may also want to consider specialist young carers careers personal advisers to provide additional support to young carers identified as NEET or at risk of becoming NEET.

⁶⁰ Ofsted (2009), 'Supporting Young Carers: Identifying, Assessing and Meeting the Needs of Young Carers and their Families'. Ofsted.

⁶¹ Carers Trust (2012), 'Pupil Premium: Support for Young Carers'. www.carers.org.

Further reading and resources about young carers and education

- Carers Trust and The Children's Society. 'Supporting Young Carers: A resource for Schools'. See <http://professionals.carers.org>.

e. Improving access to transport for young carers

Another major cause of difficulty for young carers is transport. This can be especially difficult for young carers who do not live near to their school and who spend a significant amount of time in the morning supporting parents or helping siblings get ready for school. For some this can lead to frequent lateness.

The implementation of the Disability Discrimination Act 2005 means that local authorities must provide adequate support to parents with disabilities who need support in getting their children to school. Commissioners should be aware of this and should consider putting into place mechanisms to support young carers getting to and from school.

Similarly, young carers may be unable to engage with after school clubs or other leisure activities due to transport issues and these can be exacerbated in rural areas where public transport is limited.

Kent County Council has taken steps to mitigate transport issues for young carers through the provision of free transport on buses for young carers aged 11–16 through an extension of its Freedom Pass. See <http://professionals.carers.org>.

f. Improving and maintaining the health and wellbeing of young carers

Being a young carer can often have a severe, significant and long-lasting impact on a young person's health and wellbeing. Tiredness, poor diet, interrupted sleep, back injury, stress and trauma are just some of the physical and mental health impacts young carers experience and these, if left untreated, can continue on into adulthood. Services therefore need to consider how they will support young carers with regards to their physical and mental health and wellbeing.

Having a young carers lead or champion within general practices, community mental health teams and drug and alcohol services can help achieve early identification and support of young carers.

Health visitors can play a key role in providing families with information and identifying individual children and families in need of help. They are uniquely placed to provide support at an early stage before a caring role impacts on a young carer's health and wellbeing.

School nurses are ideally positioned to play a pivotal role. By ensuring that young carers are identified early and receive timely, age-appropriate information, by spotting and addressing any emerging health needs and by ensuring that young carers are accessing appropriate health services and other support, school nurses can help reduce the negative impact on the health and wellbeing of young carers.

Dedicated support services and extra support should be available for those young carers with the most intensive caring roles and those caring for someone with stigmatised conditions such as mental ill health, substance misuse issues or HIV. For those young carers whose own mental health is affected by their caring roles, quick access to services is vital.

An annual health and wellbeing needs assessment could be employed to ensure young carers own health is unaffected and to check that young carers are registered and able to access their GP, dentist or optician.

It is important for health professionals to receive training and information on the needs of young carers in order to help them:

- Identify young carers.
- Make appropriate referrals to other agencies.
- Understand potential issues that young carers may face when for example, family members are discharged from hospital.
- Provide age-appropriate information to young carers about their parent's or sibling's condition.

g. Transition support: Seamless support from young to adult carer

For young carers, transition periods across the education system are particularly crucial times when they may struggle and become disengaged.

Similarly, the transition from a young carer, through young adult carer, to adult carer is a particularly crucial period for many young adults. They become disengaged from education and services at a time when they are required to make key decisions about their education, careers and relationships that will have long-term impacts on their lives.

Support should be seamless within and across the education system, social care and health, and lead to smooth transitions particularly as young people become carers for the first time or when young carers become young adult carers. Support should not simply finish at age 18. Achieving this may require joint commissioning that encompasses targeted support, from several agencies.

Further reading and resources young adult carers

- Becker, F, Becker S. 'Young Adult Carers in the UK: Experiences, Needs and Services for Carers aged 16–24'. See <http://professionals.carers.org>.
- NIACE. 'Young Adult Carers Access to Education and Training'. See www.niace.org.uk.

h. Personalisation: Individual budgets and direct payments

‘Support arrangements that are personalised around the specific needs of each family are more likely to produce effective outcomes.’⁶²

Personalised support for carers and those receiving care is one of the four priority areas in the updated National Strategy for Carers. The strategy states that: ‘Personalisation and a whole-family approach are complementary – it is important to look at a family’s needs as a whole but also to make sure that individual carer’s and user’s views are sought.’⁶³

The innovative, creative and flexible solutions that can come through personalisation can address the needs of the person being cared for and other members of the family. Taking such a holistic approach is central to supporting young carers. To ensure this whole family approach however, personalisation must be underpinned by strong assessment of the needs of each family member and the voice of any young carer must be heard, to ensure that their needs are met.

Where family situations have changed suddenly and where situations have not been quickly addressed, young carers have often been left with significant caring roles and some have missed considerable amounts of school. Personalisation can bring control to families and ensure that support is responsive.

Some local authorities are supporting young carers directly through direct payments. South Tyneside allocate funds from the Child and Adolescent Mental Health Services (CAMHS) budget to give young carers access to direct payments to pay for domestic support and activities for example, which might not be sanctioned through adult social care. Monies are paid directly into the bank accounts of parents who are required to produce receipts. This young carers funding has also been combined with children with disabilities funding to create an individual budget to be spent as needed, for example on a support worker, a personal assistant, a cleaner, house decoration or on dance classes for a young carer.

Personalisation offers real opportunities to better meet the needs of young carers. It can be used to build on both the strengths of the family and strengths of the young carer. If commissioners of adult services, children’s services and health services work together, more creative and effective support packages will be developed to meet the individual needs of families and prevent young carers taking on inappropriate caring roles.

⁶² Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children’s Services (ADCS) (2011), ‘Young Carers: Personalisation and Whole Family Approaches’. ADASS and ADCS.

⁶³ Department of Health (2010), ‘Recognised, Valued and Supported: Next Steps for the Carers Strategy’. HM Government.

Resource allocation

By allocating resources to the person who needs support, young people can be prevented from taking on inappropriate caring roles. It is also important that through a parent's personal budget, sufficient resources are allocated to support them in their parenting role if necessary, for example by enabling parents to transport their children to school.

Department of Health guidance on direct payments (2009)⁶⁴ states 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 coordinated between adult and children's services and other relevant departments.'

Support provided by children under 16 should not be a factor in reducing resource allocation. While 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 – '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'.⁶⁵ This is vital considering the particularly difficult transition period that young carers face at this age.

Research by Carers UK⁶⁶ shows that BAME carers are particularly likely to make use of direct payments because they are able to buy more culturally sensitive services.

i. Workforce development and raising public awareness

For any area, staff awareness and understanding of the needs of young carers and the issues they face is a vital step towards early identification and prevention, as is a strong awareness of local support services for young carers and their families.

Investment in ongoing workforce development is therefore key for staff in children's and adult services, health, education and in the voluntary sector.

Some young carers services have dedicated development workers who raise awareness and train staff on young carers' issues. They may also be responsible for strategic development, ensuring that young carers are represented in local children's plans for example. Some schools and general practices have implemented carers leads or champions who act as a conduit for training and awareness raising within their own service.

⁶⁴ Department of Health (2009), 'Guidance on Direct Payments For Community Care, Services for Carers and Children's Services'. Department of Health.

⁶⁵ Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) (2011), 'Young Carers: Personalisation and Whole Family Approaches'. ADASS and ADCS.

⁶⁶ Yeandle, S et al (2007), 'Diversity in Caring: Towards Quality for Carers'. University of Leeds, Carers UK.

Multi-agency training provides opportunities for staff to learn about each other's roles, how their area is supporting young carers and about any local referral processes that have been developed. Similarly, work shadowing between practitioners, especially across children's and adult services, is another way to engender more effective joint working.

In-house training departments, external trainers, e-learning and online films provide further training options (see below):

Further reading and resources for workforce development

- Cylix, Action for Carers (Surrey), Surrey Young Carers and Surrey County Council. 'Young Carer Aware course'. See www.cylix.co.uk.
- Royal College of General Practitioners. 'Supporting Carers in General Practice E-learning Programme'. See www.e-lfh.org.uk.
- Carers Trust and The Children's Society. 'Supporting Young Carers: A Resource for Schools'. See <http://professionals.carers.org>.
- SCIE. 'At a Glance 9: Think Child, Think Parent, Think Family'. See www.scie.org.uk.
- SCIE. 'At a Glance 32: Think Child, Think Parent, Think Family: a Briefing for Senior Managers'. See www.scie.org.uk.

j. Giving young carers a voice

Young carers are the experts on their own lives as well as the person they care for. They know from a personal perspective how their caring role affects them and their families. It is vital, therefore, that young carers are involved in the development of support plans and care packages. Similarly, services supporting young carers should have mechanisms for enabling young carers and families to engage in the ongoing development of service provision. Young carers who have been asked their opinions and views are more likely to engage with services, thus providing value for money.

Involvement of young carers can be achieved through:

- Young peoples councils.
- A local young carers forum.
- Online surveys.

Suggested outcomes and interventions for local areas to consider when designing interventions can be found in Appendix C.

Chapter 3: Do: Commissioning services to meet identified needs

This section aims to:

- Highlight what is specifically relevant to young carers and their families when agreeing a delivery model and securing the delivery of your desired service.
- Highlight equality issues and the involvement of young carers and families.
- Highlight findings around value for money.

When setting contracts and service specifications, it is important to be mindful of the following points:

- The importance of involving young carers and families in setting service specifications to ensure that service-level targets and measuring reflect the things that make a direct impact on the lives of young carers and their families and are valued by them.
- Young carers and their families report the importance of consistent individual professional involvement⁶⁷ and in particular the consistency of having a key worker in order for trust to be built. Trust in a key worker, which takes time to build, facilitates better engagement⁶⁸ for young carers and families and therefore more effective interventions.
- That the skills and experience of staff are key.⁶⁹
- To recognise the importance of long-term interventions and continuity of support across transitions, on improving social value and positive long-term individual outcomes.
- The gathering of good evidence and evaluation can be time intensive and therefore must be factored into costs.
- The value of measuring and tracking wellbeing and the impact of wellbeing locally.

⁶⁷ Association of Directors of Adult Social Services (ADASS) and Association of Directors of Children's Services (ADCS) (2011), 'Signposts, See Me, Hear Me, Talk to Me – Talk to My Family as Well, Working Together To Improve Outcomes for Young Carers in Families Affected by Enduring Parental Mental Illness or Substance Misuse'. ADASS and ADCS.

⁶⁸ York Consulting (2011), 'Turning Around the Lives of Families with Multiple Problems – an Evaluation of the Family and Young Carer Pathfinders Programme'. Department for Education.

⁶⁹ York Consulting (2011), 'Turning Around the Lives of Families with Multiple Problems – an Evaluation of the Family and Young Carer Pathfinders Programme'. Department for Education.

Equality

As public authorities, both local authorities and Clinical Commissioning Groups have general and specific duties under the Equality Act 2010, designed to integrate consideration of advancing equality.

Carers Trust's work with young carers services indicates that there are groups of young carers who are less likely to be identified and supported because of their caring roles, so widespread involvement of young carers, particularly those at risk of being overlooked, may require specialist services to be commissioned.

The Equality Act 2010 requires commissioners to ensure that services do not directly discriminate against carers, including young carers, making it all the more important to identify and include young carers who may be currently unable to access appropriate information or support.

Value for money

'In one family alone, there was acceptance by a range of stakeholders that the children in the family would have ended up in care. On a cost benefit analysis alone, this intervention paid for the whole project'.⁷⁰

Having a clear understanding of the value of services for young carers will realistically be difficult to measure, since there are so many factors at play. However, when considering value for money it is important to remember that since there is such a wide range of possible outcomes for young carers, the cost benefits are likely to span across social care, health, education and other areas.

Moreover, there are likely to be further long-term savings to the national purse that come from improved career prospects as concluded by the Audit Commission: 'Over their lifetime, young carers can be expensive to the public purse. Short-term costs (16 to 18) of not being in work or training may not be significantly more than the cost of learning or interventions. However, over the medium term (19 to 59) and long term (60 and over) the costs of being a NEET young carer can be high. With suitable support and access to work or learning young carers can move into sustained education, employment or training.'⁷¹

The picture is made even more complicated when we are considering the outcomes not only for young carers but their families too.

⁷⁰ Hitchin, J, Bolsin, J (2012), 'Evaluation of Whole Family Intervention Pilot Programme 2010–11'. Carers Trust and Renaisi.

⁷¹ Audit Commission (2010), 'Against The Odds, Targeted Briefing – Young Carers'. Audit Commission.

However, some specific work on value for money has been carried out, such as on the interventions in the Young Carers Pathfinder Programme (2007), where conservative assessments of the return on investment indicated that for every £1 spent, there was a saving of was £1.89.⁷²

Previous research⁷³ commissioned by The (former) Princess Royal Trust for Carers and Crossroads Care highlighted that for every £1 invested in a young carers service (specifically, targeting interventions on young carers affected by parental substance misuse and parental mental ill-health), the saving to the Exchequer and wider society as a whole is £6.72.

The (former) Princess Royal Trust for Carers report, Social Impact Evaluation of Five Carers' Centres Using Social Return on Investment⁷⁴ found that the damage value of a young person who is NEET is £104,945 over their lifetime. Considering that young adult carers aged between 16 and 18 years are twice as likely to be NEET⁷⁵, supporting this group through respite and educational support to remain in education will have considerable cost savings.

Involving young carers and families

As well as consulting young carers as part of the local needs assessments, young carers and their families can be further involved in a meaningful way in the procurement process, such as visiting potential service providers and making recommendations.

Once a mechanism for the involvement of young carers and their families has been established, as in the example below, the commissioning process can be further enhanced and guided by further ongoing participation of young carers and families in activities such as recruitment and evaluation of service provision.

⁷² York Consulting (2011), Turning Around the Lives of Families with Multiple Problems – An Evaluation of the Family and Young Carer Pathfinders Programme'. Department for Education.

⁷³ Crossroads Care, The Princess Royal Trust for Carers (2008), 'Economic Evaluation of Young Carers' Interventions'. Crossroads Care and The Princess Royal Trust for Carers.

⁷⁴ The Princess Royal Trust for Carers, Baker Tilly (2011), 'Social Impact Evaluation of Five Carers' Centres Using Social Return on Investment'. The Princess Royal Trust for Carers.

⁷⁵ Audit Commission (2010), 'Against the Odds', Audit Commission.

Norfolk Young Carers Forum – commissioning involvement

Five young carers from the forum were trained to become members of a young carers panel in order to scrutinise application submitted for a tender. Each bidding organisation was asked to submit a short young-person friendly summary of how they would provide their service. These were anonymised (as some young carers were being supported by bidding organisations).

The young carers scored the summaries against criteria they had worked out with the Commissioning Officer and scores from the adult panel and the young carers panel were then combined. Typically, 20% of the overall score was attributed to the young carers' evaluation meaning the local authority retained overall accountability for the commissioning decisions, but gave the young carers significant influence in the decision. Where results were tied, the scores from the young carers panel were taken as the deciding vote – ensuring the young carers' involvement was seen as meaningful.

Chapter 4: Review: Evaluating the impact of services

This section aims to:

- Discuss the importance of measuring impacts and what needs to be measured, and suggests ways this can be done.
- Support commissioners to understand whether or not the services that have been commissioned have had a positive impact on young carers and their families and whether the outcomes in a local plan have been achieved.

'A detailed evaluation of the different approaches and their impact on young carers and their outcomes is lacking.'⁷⁶

Measuring outcomes for young carers is crucial in determining the success of services offered. What matters to young carers and their families, is whether a service has improved their life and this needs to be reflected in what is measured.

Understanding is emerging about what works for young carers and their families and why it works, but concerted action at local level to generate consistently collected information that is accurate, timely and relevant to the outcomes that young carers and their families are seeking, continues to be needed to inform local commissioning. Commissioners, therefore, should set up mechanisms – as highlighted in the 'Understand' section of this resource, to ensure that evaluation is informed by families and young carers themselves.

Successful measuring of the correct outcomes will show whether interventions are making a difference, or not. It will identify which elements are working, which are not and which are value for money. This knowledge will guide and inform future interventions.

What to measure

The suggested outcomes in Appendix C reflect what young carers and families nationally have said is important. These outcomes are manifold and reflect the parallel approach to supporting both the family as a whole and the young carer directly. They also reflect how services should aim to improve a wide range of areas in the lives of young carers, such as their education, career prospects and their physical and mental health.

⁷⁶ Department of Health (2008), 'Carers at the Heart of 21st Century Families and Communities, A caring System on Your Side. A Life of Your Own.' HM Government.

Furthermore, the support of young carers and their families involves both hard and soft outcomes and both are important.

An intervention that increases a young carer's school attendance is valuable, as is an intervention that improves a young carer's psychological wellbeing. Both however, are important for the young carer to achieve their full educational potential.

Commissioners must resist the temptation to not invest in or to not measure those things (such as psychological wellbeing) that drive longer term changes to outcomes.

The Young Foundation Framework of Outcomes

The Young Foundation has developed a Framework of Outcomes for Young People⁷⁷ which is 'designed to highlight the fundamental importance of social and emotional capabilities to the achievement of all other outcomes for all young people'. The framework 'proposes a model of seven interlinked clusters of social and emotional capabilities that are of value to all young people, supported by a strong evidence base demonstrating their link to outcomes such as educational attainment, employment, and health.'

A summary version has been published by NCVYS.⁷⁸

In a whole family approach, measuring the outcomes for the parent and for the whole family is therefore important. There are a variety of tools that aim to do this such as the Family Star™⁷⁹ which covers eight areas of parenting essential to enabling children to thrive.

Cross-cutting impacts

As well as consideration of long-term employment and earnings outcomes for young carers and their families, joint commissioning increases the need to clearly identify the cross-cutting and economic impacts that different interventions make in the areas of health, social care (both children's and adult services), education and possibly the criminal justice system. This of course is problematic since some improved outcomes will be the result of collaborative work. However, the significant contributions that one service might have on another must be recognised. Even limited interventions, such as timely and appropriate referrals to other agencies, will indicate value from a service across the piece.

⁷⁷ <http://www.youngfoundation.org/publications/reports/framework-outcomes-young-people>, accessed October 2012.

⁷⁸ <http://www.ncvys.org.uk/UserFiles/121004%20Factsheet%205%20-%20Framework%20of%20outcomes%20for%20young%20people.pdf>, accessed October 2012.

⁷⁹ Developed by Triangle Consulting Social Enterprise Ltd.

To evaluate this corporate value, commissioners might consider drawing on evidence such as:

- Satisfaction surveys, testimonials or quotes from wider services affected by a service supporting young carers (for example, services which have received referrals).
- Referral numbers made from one service to another.

By evaluating this corporate value, indications should emerge of how the whole is greater than the sum of the parts.

Measuring outcomes for young carers

One way of measuring what matters to young carers and their families at an individual level, service level and at a specific intervention level, is to use the Manual for Measures of Caring Activities and Outcomes.⁸⁰ This is now being increasingly used by young carers services across the UK. It contains a range of tools relevant for assessment and evaluation work with young carers that can help establish baseline data for both the amount of caring undertaken as well as the impact of caring and demonstrate the distance travelled as a result of interventions.

These tools should not be used in isolation, rather they should complement what is already known about a young person and their family, including existing information gathered in the course of formal assessment processes (for example, CAF or a core assessment). See: <http://professionals.carers.org>.

Monitoring of the number of young carers who are NEET would be a useful gauge of the success of a local area and where schools work is taking place, outcomes around school attainment and attendance could be measured as done by Oxfordshire County Council.

A range of both quantitative and qualitative measures are important. Commissioners should be mindful that many young carers services will be using a variety of methods that bring added value to measuring outcomes and user satisfaction such as:

- Satisfaction surveys.
- Annual feedback forms.
- Focus groups.
- Quotes collected from young people and families.
- Using individual support planning tools.
- Case studies.
- Photo/film evidence.

Further reading and resources on outcomes

The Department for Children, Schools and Families. 'Turning the Curve Stories'. See www.education.gov.uk.

⁸⁰ Joseph, S, Becker, F, Becker, S (2012), 'The Manual for Measures of Caring Activities and Outcomes for Children and Young People'. Carers Trust.

Appendix A: Findings from interventions

‘A detailed evaluation of the different approaches and their impact on young carers and their outcomes is lacking.’⁸¹

We are just starting to begin to understand what works and why. The following appendices highlight some of the key issues emanating from recent evaluations of interventions supporting young carers and their families.

The Young Carer Pathfinders Programme 2007

Evaluated by York Consulting in 2011.⁸²

Overview

The Family Pathfinder programme was launched in 2007 with the aim to develop local responses to the needs of families who faced ‘multiple and complex social, economic, health and child problems.’

Findings

- The research brief states that ‘The evidence from this study presents a compelling case for LAs and their partners to develop and implement intensive family intervention with families with multiple and complex needs.’
- Achieving improved and sustainable outcomes for families was dependent on the use of a key worker responsible for providing and coordinating effective support for families.
- Results showed significant improvement in outcomes for a third (31%) of the families supported by the Young Carer Pathfinders. Around 13% however showed an escalation in need.
- On exit from support, the evidence suggests that three fifths (60%) of children and young people with inappropriate levels of caring (that is, caring role has a negative impact on children and young people) showed an overall improvement in their situation and for nearly a third (32%), concerns were removed.

⁸¹ Department of Health (2008), ‘Carers at the Heart of 21st Century Families and Communities, A caring System on Your Side. A Life of Your Own’. HM Government.

⁸² York Consulting (2011), Turning Around the Lives of Families with Multiple Problems – An Evaluation of the Family and Young Carer Pathfinders Programme’. Department for Education.

- Areas were also able to demonstrate savings such that for every £1 spent, the Young Carer Pathfinders generated a financial return of £1.89.
- In the delivery of improved outcomes, the evaluation highlighted three ‘critical and interrelated components of delivery,’ with:
 - A persistent and assertive key worker role (highly skilled, credible and experienced professional).
 - A robust framework of support: including a comprehensive assessment of the needs of all family members and a multi-disciplinary Team Around the Family approach.
 - An intensive and flexible, family focused response.

The full evaluation can be found at www.education.gov.uk.

The Innovation Fund 2009

York Consulting Limited Liability Partnership (YCL) was commissioned to evaluate the projects developed and delivered through The Innovation Fund.⁸³

Overview

In 2009, on behalf of The National Young Carers Coalition, The former Princess Royal Trust for Carers managed the Innovation Fund, a funding programme that administered funding to services in order to ‘lift young carers out of inappropriate caring roles and to develop sustainable solutions’.

Services delivered a wide range of interventions for families, including whole family support, therapeutic work, family group work and respite activities and developed partnerships with other agencies such as schools, adult services and health teams.

Findings

- Although services faced a number of challenges including engaging hard to reach families in group activities, the approaches and support have helped strengthen the evidence base for continuing to develop whole family working.
- Based on evidence from the Multidimensional Assessment of Caring Activities (MACA) and Positive and Negative Outcomes of Caring (PANOC) data,⁸⁴ it was estimated that ‘for a third of the families, the impact was significant and resulted in reduced levels of caring by young carers. For others the impact was more on a family’s ability to cope with the issues they faced’.

⁸³ Ronicle J, Starks, L, York Consulting LLP (2012), ‘Evaluation of the Innovation Fund 2012’. Carers Trust.

⁸⁴ Joseph, S, Becker, F, Becker, S (2012), ‘The Manual for Measures of Caring Activities and Outcomes for Children and Young People’. Carers Trust.

The main areas of impact were:

- Improved wellbeing.
- Reduced isolation.
- Improved family functioning.
- Greater understanding of issues within the family.
- Increased resilience.
- Improved happiness.

As part of its recommendations, the evaluation highlights the following as particular features of the support that led to positive impacts:

- The Family Support Worker role was in particular a valuable addition to services. And the Innovation Fund also demonstrated the added value the voluntary sector can bring to services for the whole family.
- The evaluation concludes that for some families who received bespoke support from services, their support can be considered excellent value for money.

The full evaluation will shortly be available at <http://professionals.carers.org>.

The Whole Family Intervention Pilot Programme 2010–2011

The former Princess Royal Trust for Carers commissioned the evaluation of this programme by Renaisi (2012).⁸⁵

Overview

This programme, funded by Comic Relief, developed two partnerships between two voluntary agencies – a young carers service from The former Princess Royal Trust for Carers network of carers’ centres and a Family Action service, typically focused on supporting parents within families. The strength of the partnerships lay in bringing together the different skills from each partner. The interventions aimed to support families as a whole and broke down into three activity types: practical; emotional and relational (involving activities to build roles, responsibilities and routines within the family).

The activities are broken down into four categories:

- 1 Supporting the young person with their caring role.
- 2 Supporting the family to adapt.
- 3 Supporting the parent.
- 4 Bringing in external support.

⁸⁵ Hitchin, J, Bolsin, J (2012), ‘Evaluation of Whole Family Intervention Pilot Programme 2010–11’. Carers Trust and Renaisi.

Findings

- Family relationships saw significant improvements and young carers saw positive changes in their attitudes to caring. The qualitative data supported a relationship between the improvement in the family relationships and the young carer's attitude to caring.
- Qualitative findings suggest that 'many of the caring relationships were quite complex and engrained in the families and so it was not easy to reduce caring roles in these families in short timescales.'

This was a very small study and the limited data available did not find significant change in the volume of the caring. The cases (of impact on the volume of caring) where a shift was seen were those where external support – perhaps in the form of a care worker – had been brought in to take some of the caring role from the young carer.

- The qualitative findings did find however, that the whole family approach was more successful and relevant to the young carers than other types of support available to them in the following ways:
 - Worry – the project helped young carers who were too worried about the person they care for to engage in school or wider support services.
 - Trauma – it helped rebuild relationships following traumatic episodes which had often resulted in the need for caring.
 - Root causes – it allowed time to work backwards into the family, from symptoms displayed to the root causes.
 - Parenting – it helped parents improve their parenting skills to relieve the young carer from taking on those roles.
- As highlighted elsewhere, interventions that were successful were found to be where families could identify with and trust staff.
- The research highlighted the value of starting with the young person rather than the parent as a way to build trust and relationships between services and the family.

And that if referrals were made through the young carer (for example, through a school referral) rather than a parent, then outcomes were more successful as the focus remained on the young carer and support continued irrespective of families not wishing to engage.
- The partnership working increased the awareness of staff and agencies of cross-family issues and facilitated links with other services such as mental health services, and parenting services.

The full evaluation will shortly be available at <http://professionals.carers.org>.

Nottingham University analysis of project interventions

An analysis of the results of 17 project interventions that had used the Outcomes Measuring Tool to measure both the amount of caring and the positive and negative outcomes of caring, found the following:

- 1 There was not a significant reduction (as measured by the MACA) in the amount of caring activities performed by young carers across both programme evaluations.
- 2 Individual projects are at their most effective in reducing the overall amount of caring when they are providing help to those young people with greater levels of caring in the first place (that is, those whose pre-intervention MACA scores are high).
- 3 Preventing an increase in caring, or reducing the amount of caring done by children, will require interventions that are targeted specifically on controlling or reducing caring tasks.
- 4 There was no significant increase in the positive outcomes for young carers. However, positive outcomes were already high across the projects even at pre-intervention stage.
- 5 The negative outcomes of caring decreased for both programmes. These include a reduction in young carers' sense of loneliness, sadness and isolation.
- 6 Reducing the negative outcomes of caring may be a more important aim than increasing the positive outcomes, especially where young carers come to a project in the first place with a high negative score on the PANOC.

The following illustration can help explain points 4 and 5:

A man who had previously been unhappy at work asked his wife if she thought he was now a happier person. She replied, 'Darling, I don't think you're happier now but you are less miserable.'

When commissioning services, commissioners may wish to consider focusing services at those young carers who are at the higher end of the MACA scale.⁸⁶

The Young Carers Grants Programme 2008–2011

The former Princess Royal Trust for Carers commissioned the evaluation of this programme.⁸⁷

⁸⁶ As highlighted previously, it is important to also consider the value of early intervention and prevention. Strong assessments indicating family strengths and risks should also inform practitioners about current and future support needs.

⁸⁷ Barham, J, Day, L, Gardner, R, ECORYS (2012), 'Getting to the Outcomes: The Young Carers Grants Programme 2008–2011: A Qualitative Study of Three Funded Projects'. Carers Trust.

Overview

Using funding from Comic Relief, The former Princess Royal Trust for Carers funded 12 organisations aiming to ‘identify and reduce the extent of inappropriate caring roles taken on by children and to achieve positive outcomes for the young carer and person being cared for’. Comic Relief also provided funding towards the development of The Measures of Caring Activities and Outcomes for Children and Young People resource.

Findings

The evaluation of the programme highlighted a number of common factors that might help explain the caring outcomes. This analysis of factors is helpfully divided under headings based on the findings from the PANOC and MACA tools in the Measures of Caring Activities and Outcomes for Children and Young People. Suggestions are given to services under each heading:

Increasing positive outcomes from caring

It is suggested (among other things) that services consider giving attention to the wider needs of young carers; adopting a multi-agency approach; engaging a wide range of local organisations and adopting a differentiated approach for working with young carers of different ages and abilities.

Reducing negative outcomes from caring

It is suggested (among other things) that services consider developing a ‘clear project support worker role’ that allows for sustained and intensive one-to-one support; providing emotional support and opportunities for participation in group work.

Reducing inappropriate caring roles

It is suggested (among other things) that services consider adopting a targeted, sustained approach aimed at those with the heaviest caring roles; working with the family to encourage discussion about caring roles, their impact and how to address this; working closely with partner organisations to monitor caring roles and ensuring the engagement from both children’s and adult social care teams to consider wider options for reducing caring roles.

Wider learning points included:

- The importance of dealing with the emotional aspects as well as aiming to selectively reduce caring roles.
- Building trusting relationships.
- The importance of adult social care and a multi-agency approach.
- The importance of negotiation with the family (and education of those receiving care) where significant caring reductions were needed.
- The importance of flexibility and rapid response.
- The importance of improved relationships within families.

The full evaluation will shortly be available at <http://professionals.carers.org>.

Appendix B: Quick checklists based around the commissioning cycle

Understand – Quick checklist of key points		✓
Nationally		
Be aware of the national policy framework, statistics and data for young carers		
Be aware of examples of good practice nationally		
Locally		
Identify the needs of young carers and families and positive outcomes relevant to them		
Use of a range of methods for gaining feedback from young carers and families including:		
<ul style="list-style-type: none"> • Consultation events and focus groups • Engagement through young carers services/a local young carers forum • Use of online technology • Engaging with young carers through schools, youth services, health and social care and other settings 		
Identify the outcomes that current provision achieves for:		
<ul style="list-style-type: none"> • young carers and their families • young adult carers • hard to reach groups, sibling carers and different age groups • workforce development • local priorities as set out in a local young carers strategy 		
Consider the potential impact on young carers and families if existing provision was lost		
Identify and analyse the gap between young carers' and families' needs and current service provision		
Identify and agree the local priorities for young carers and their families		

Plan – Quick checklist of key points	✓
Ensure the views of young carers and families are reflected	
Ensure alignment with a local young carers strategy	
Ensure alignment with joint working protocol between children’s and adult services	
Ensure alignment with referral pathways for young carers	
Plan to build the capacity of both targeted and universal services for young carers	
Plan to develop the workforce and raise public awareness of young carers	
Plan provision for different age groups and hard to reach groups	
Plan interventions with a whole family approach, and consider:	
<ul style="list-style-type: none"> • A key worker approach 	
<ul style="list-style-type: none"> • Use of whole family assessments 	
<ul style="list-style-type: none"> • Family Group Conference or similar 	
<ul style="list-style-type: none"> • Building relationships within the family 	
Consider potential of developing partnerships	
Plan targeted support for young carers and families	
Plan for identification mechanisms to be built in across the local area	
Plan for early intervention and prevention to be built in across the local area	
Plan to develop a local ‘visible and transparent offer’ of support for young carers and their families	
Plan for the collation of data on young carers (such as school attainment)	
Consider joint commissioning with schools	
Plan to support young carers and young adult carers through their education and career paths	
Plan to improve and maintain the health and wellbeing of young carers	
Commission support for young adult carers	
Plan to improve access to transport for young carers	
Consider the potential of individual budgets and direct payments	

Do – Quick checklist of key points	✓
Ensure young carers and families are directly involved in the commissioning process –setting service specifications and in the evaluation of bids	
Identify clear outcomes to be delivered for service users	
Ensure that commissioning supports consistency of service delivery staff	
Where possible, look to commission long-term interventions	
Factor in the cost of measuring, monitoring and evaluating impact	
Consider hard to reach groups of young carers when assessing equality of provision	
When planning to evaluate value for money consider:	
<ul style="list-style-type: none"> • The cross-cutting or wider social value and the use of models such as social return on investment 	
<ul style="list-style-type: none"> • The long-term impact 	
Invest in measuring interventions that drive long-term change	

Review – Quick checklist of key points	✓
Ensure that evaluation is informed by families and young carers themselves	
Put in place mechanisms that measure interventions which drive longer term changes to outcomes	
When measuring outcomes, consider the importance of social and emotional capabilities that underpin subsequent future outcomes	
Evaluate the outcomes for young carers, parents and the whole family	
Evaluate the corporate (or wider social) value of interventions	
Evaluate the impact on other services	
Make use of the Manual for Measures of Caring Activities and Outcomes	
Include a range of both quantitative and qualitative monitoring	
Make use of existing methods of evaluation as appropriate	

Appendix C: Suggested outcomes and interventions for young carers and their families

The National Strategy for Carers states⁸⁸ that by 2018 every carer should be:

- 1 Recognised and supported as an expert care partner.
- 2 Enjoying a life outside caring.
- 3 Not financially disadvantaged.
- 4 Mentally and physically well; treated with dignity.
- 5 Children will be thriving, protected from inappropriate caring roles.

Its vision for young carers 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)'. Brackets added.

In the refresh of the strategy (Recognised, Valued and Supported: Next Steps for the Carers Strategy, 2010) four priority areas were identified for action over the next four years. These priorities relate back to the outcomes that the Government is seeking to achieve:

- Priority 1 'Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.'
- Priority 2 Enabling those with caring responsibilities to fulfil their educational and employment potential.'
- Priority 3 'Personalised support both for carers and those they support, enabling them to have a family and community life.'
- Priority 4 'Supporting carers to remain mentally and physically well'.

The following tool offers suggested outcomes and interventions for service for young carers and their families. It aims to support commissioners to achieve the overarching outcomes and priorities set out above. In developing your own local outcomes, be mindful of the hard to reach groups identified locally and those discussed in the 'Plan' section.

Carers Trust aims to develop and refine the outcomes below. We would welcome your comments on these as well as suggestions for additional outcomes. Please email outcomes@carers.org.

⁸⁸ Department of Health (2008), 'Carers at the Heart of 21st Century Families and Communities, A Caring System on Your Side. A Life of Your Own.' HM Government.

Identified local needs/priorities	Suggested outcomes	Suggested interventions or provision	Service provider
	<p>Young carers are identified early and supported</p> <ul style="list-style-type: none"> ■ Young carers are identified early before their caring role impacts negatively on them. ■ Young carers and families receive timely support. ■ Young carers' health, wellbeing and development are protected. 	<p>Identification of young carers</p> <ul style="list-style-type: none"> ■ Children's and adult services work together to identify young carers early. ■ Health services assist in early identification of young carers. ■ Schools and colleges assist in early identification of young carers. ■ Other universal services and the voluntary sector assist in early identification of young carers. ■ Training for professionals on young carers issues. ■ General awareness raising in the community. 	
	<p>Young carers can have breaks from their caring roles and are less isolated</p> <ul style="list-style-type: none"> ■ Young carers have a break from caring responsibilities at weekend activities, after school or evening clubs, or holidays. ■ Young carers are less isolated. ■ Specific groups (for example, rural young carers) are less isolated. ■ Young carers make friends and have fun. ■ Young carers access peer support from others in similar situations. ■ Young carers can access transport to support groups and activities. ■ Young carers receive online support. ■ Young carers enjoy activities with their families. 	<p>Activities and breaks for young carers</p> <ul style="list-style-type: none"> ■ Young carers clubs or group activities. ■ Transport provided to activities. ■ Transport schemes that benefit young carers. ■ Local or national online support for young carers. ■ Family activity days. ■ Day trips for young carers. ■ Residential trips. ■ Holidays for young carers. 	

	<p>Young carers receive advocacy when required</p> <ul style="list-style-type: none"> ■ Young carers receive advocacy at school or college. ■ Young carers receive advocacy at hospital discharge of the person they care for. 	<p>Advocacy for young carers</p> <ul style="list-style-type: none"> ■ Support through a young carers support worker. ■ Advocacy service. 	
	<p>Young carers can access brokerage services when required</p> <ul style="list-style-type: none"> ■ Young adult carers have support to access personal budgets. 	<p>Brokerage for young carers</p> <ul style="list-style-type: none"> ■ Services to support young adult carers to access a carer's direct payment. 	
	<p>Policy and services are shaped by young carers</p> <ul style="list-style-type: none"> ■ The voice of young carers helps to steer local and national policy. ■ Commissioning and local service design is developed around what young carers and families say they need. 	<p>Consulting young carers</p> <ul style="list-style-type: none"> ■ Channels established to ensure young carers and families feed into Health and Wellbeing Boards. ■ A young carers forum. ■ Regular consultation of young carers and families. ■ Consultation events. ■ Young carers and families input into local networks and steering groups. ■ Surveys / online surveys. 	
	<p>Young carers develop skills to build their resilience</p> <ul style="list-style-type: none"> ■ Young carers develop life skills through activities such as first aid, moving and handling, financial / budgeting skills. 	<p>Caring support and training</p> <ul style="list-style-type: none"> ■ Provision of targeted life skills. 	

	<p>Young carers are supported at key transition periods</p> <ul style="list-style-type: none"> ■ Young carers are supported across school transitions. ■ Young adult carers receive dedicated and specific support. ■ Young carers and young adult carers receive specific careers guidance. ■ Fewer young adult carers are NEET. ■ More adult young carers are in education or employment. ■ Young adult carers who are students are less isolated and greater numbers remain in education. ■ Young carers receive seamless support as they move into an adult caring role. ■ Young carers do not disengage from services. 	<p>Support with changes and transitions</p> <ul style="list-style-type: none"> ■ Support group for young adult carers. ■ Support in colleges and/or universities. ■ Dedicated and specialist workers for young adult carers. ■ Outreach service for young adult carers. ■ Support for young adult carers into employment and further education. ■ Partnership work with adult carers services. ■ Training professionals on young carers issues. 	
	<p>Young carers are supported through their education</p> <ul style="list-style-type: none"> ■ Staff understanding of young carers' issues and needs is increased. ■ All pupils' understanding of young carers, caring issues and disability is increased. ■ Young carers are identified, assessed and receive support. ■ Young carers and families are referred to appropriate support. ■ Engagement with the school is maintained by the young carers and parents. 	<p>Support in schools and colleges and higher education</p> <ul style="list-style-type: none"> ■ Strong partnership work with social care and health services. ■ Strong partnership work with a local young carers service or other voluntary services. ■ Schools develop and implement a policy for young carers. ■ Schools have a staff member to lead on coordinating support for young carers. ■ Schools implement a whole school approach using Supporting Young Carers: A Resource for Schools. 	

	<ul style="list-style-type: none"> ■ Young carers' attendance is increased. ■ Young carers are less bullied. ■ Young carers' achievement and attainment are raised. ■ Young carers are happy in school. ■ Parents are able to engage in their child's education. ■ Young carers have equal opportunity to continue further/higher education as their peers. ■ Young carers are identified and supported at FE/HE establishments. 	<ul style="list-style-type: none"> ■ School drop in or weekly peer support group. ■ Delivery of personal, social, health and economics education. ■ Staff are trained on how to support young carers. ■ Young carers are supported by school nurse. ■ Young carers peer mentoring and/or buddying schemes. ■ One-to-one support within schools. ■ Homework support for young carers. ■ Schools implement a 'young carers card'. ■ Targeted support at transition periods. ■ The Pupil Premium is used by schools to support young carers. ■ The attainment and attendance of young carers is monitored. 	
	Emergency planning is in place	Emergency planning support	
	<ul style="list-style-type: none"> ■ Crisis or emergency plans are developed and put in place. ■ School attendance is increased. ■ Engagement with school is maintained. ■ Young carers are less worried. 	<ul style="list-style-type: none"> ■ Development with young carers and families of emergency or crisis support plans. 	
	Young carers can access emotional support and counselling	Emotional support and counselling	
	<ul style="list-style-type: none"> ■ Young carers have someone to talk to and a listening ear. ■ Young carers access formal counselling and other dedicated services when required. ■ Young carers emotional and mental health is improved. 	<ul style="list-style-type: none"> ■ CAMHS support. ■ Counselling service. ■ Mentoring or befriending service. ■ Support workers or young carers. ■ Online support. ■ One-to-one support. 	

	<p>The health and wellbeing of young carers is protected or improved</p> <ul style="list-style-type: none"> ■ Young carers' physical, emotional and mental health is protected/improved. ■ Young carers eat healthily. ■ Young carers take regular exercise. 	<p>Supporting health and wellbeing</p> <ul style="list-style-type: none"> ■ Young carers are supported to remain healthy and adopt healthier lifestyles. ■ Health professionals are trained in supporting young carers and their families. 	
	<p>Young carers and their families live in appropriate accommodation</p> <ul style="list-style-type: none"> ■ Families are supported in accessing housing adaptations. ■ Young adult carers are supported in accessing appropriate accommodation. 	<p>Housing support</p> <ul style="list-style-type: none"> ■ Housing services working in partnership with social care services/community care services. 	
	<p>Young carers and their families receive timely and appropriate information</p> <ul style="list-style-type: none"> ■ Young carers receive information about support and services available. ■ Young carers are identified, assessed and receive support. 	<p>Information provision</p> <ul style="list-style-type: none"> ■ Age-appropriate information. ■ Access to information via a range of services. ■ Information made available on websites and through social media. ■ Information made available at for example, GP surgeries, pharmacies, libraries. 	
	<p>Families and young carers receive timely advice on benefits and finance</p> <ul style="list-style-type: none"> ■ Young carers and their families have better understanding of benefits available to them. ■ Families receive a review of family benefit entitlements and supporting in accessing the correct benefits or grants. 	<p>Money and benefits advice</p> <ul style="list-style-type: none"> ■ Specific financial/benefits advice. ■ Life skills training for young carers on finance and budgets. ■ Direct payments and are promoted to young adult carers (aged 16–17). 	

	<ul style="list-style-type: none"> ■ Families receive the benefits they are entitled to. ■ Young carers develop financial life skills. ■ Families receive support to manage their finances. 	<ul style="list-style-type: none"> ■ Dedicated service to support young adult carers to access a carer's direct payment. 	
	<p>Young carers are supported by peers</p> <ul style="list-style-type: none"> ■ Young carers are less isolated. ■ Young carers gain confidence and trust. ■ Young carers develop friendships and social lives are improved. 	<p>Peer and community support</p> <ul style="list-style-type: none"> ■ Peer support groups after school. ■ Befriending or mentoring scheme. ■ Use of technology and online services such as YCNet. 	
	<p>Young carers are supported through a whole family approach</p> <ul style="list-style-type: none"> ■ Young carers are identified, assessed and receive support. ■ Services provide additional input into safeguarding work. ■ Holistic support planning around the needs of the family. ■ Alternatives to young carers' inappropriate caring roles found. ■ Fewer young carers have inappropriate caring roles. ■ Parents and other family members are supported to access other services. ■ Parents are supported in their parenting role. ■ Parents given individual budgets to support parenting. 	<p>Whole family support</p> <ul style="list-style-type: none"> ■ An active local joint working protocol between adult and children's services. ■ Strong links with children's services. ■ Strong links with adult services. ■ Strong links with other local services and agencies. ■ Whole family assessments. ■ Family visits. ■ Signposting or referring of family members. ■ Clear information for families. ■ Delivering or facilitating parenting support. ■ Delivering or facilitating family mediation. ■ Support for families with roles, relationships and responsibilities. 	

	<ul style="list-style-type: none"> ■ Families access services and benefits which they are entitled to. ■ Families support networks are strengthened. ■ Families receive advocacy. ■ Family relationships are strengthened. ■ Young carers have fun with their families. 	<ul style="list-style-type: none"> ■ Family group conferences or equivalent. ■ Positive activities for the family. ■ Input into safeguarding work. 	
	<p>Young carers are supported into work and training</p> <ul style="list-style-type: none"> ■ Young carers develop life skills such as first aid and financial skills, through activities. ■ An increased number of young adult carers in education and employment. ■ An increased engagement in out-of-school activities and accreditation schemes. 	<p>Work and training</p> <ul style="list-style-type: none"> ■ Activities to build life skills for young carers. ■ Carers advice and support for young adult carers to get into employment or training. 	
	<p>The local workforce is trained on how to support young carers and their families</p> <ul style="list-style-type: none"> ■ Professionals in: <ul style="list-style-type: none"> – health services – social care – education – early years – youth services – and the third sector are trained on young carers' issues and can support young carers and families more effectively. ■ Professionals know where to refer young carers and their families for support. 	<p>Skilling the workforce</p> <ul style="list-style-type: none"> ■ Promotion of 'transparent offer' for how a local area supports young carers. ■ Work shadowing between practitioners in children's and adult services. ■ Multi-agency training. ■ Service carers champions. ■ E-learning. 	

	The community understands the issues faced by young carers	General awareness raising	
	<ul style="list-style-type: none"> ■ Awareness of young carers in the community is increased. ■ The community is aware of the support available to young carers and their families. 	<ul style="list-style-type: none"> ■ Promotion of 'transparent offer' for how a local area supports young carers. ■ Services promote how they support young carers. 	



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Registered as a company limited by guarantee in England and Wales No. 7697170.
Registered office: 32–36 Loman Street, London SE1 0EH.

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