Whole Family Pathway

A resource for practitioners

The importance of the whole family approach

Young carers do not care in isolation. Although they may require support themselves, their needs must be considered and met in the context of their whole family.

Using the Whole Family Pathway will help practitioners to implement the duties outlined in the Care Act 2014, the Children and Families Act 2014, and the Health and Care Act 2022 for young carers and their families. Local authorities should consider how they can support the needs of the cared-for person or people to both reduce and prevent young carers from taking on excessive or inappropriate responsibilities.

It is important to make sure that the same processes or pathways are followed, no matter how the family first makes contact with an agency. Young people must be protected from caring roles that might negatively impact their life changes. The Whole Family Pathway is a 'map' that all professional agencies can follow to see what choices, responsibilities, and lines of accountability for services might be available.





Young carers and families are experts on their own lives. It falls to professionals across all sectors to include them in shaping the personalised and integrated responses that best respond to their needs. This applies equally whether care needs arise as a result of mental or physical illness or disability, substance misuse, and whether a parent or a sibling is the focus of support.'

No Wrong Doors: 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, 2015.

Effective responses to the needs of young carers and their families are available through this Whole Family Pathway.

Links

No Wrong Doors

Contents

How to use the Whole Family Pathway	4
ntroduction: why use the Whole Family Pathway?	5
Young carers and their families: definitions and context	7
Whole family approaches	15
Referrals: what to consider for:	
a parent with an illness or disability	18
a child in the family or an indentified young carer	19
a child with an illness or disability	20
Consulting with families and service provision	21
Assessment	23
Health: the role of health agencies	38
Education	39
Housing	40
Nature of illness and disability	41
Drug and alcohol misuse	43
_ocal young carers services and support	44
Online resources for young carers and their families	46
Organisations working for young carers and their families	48
References and resources	49

How to use the Whole Family Pathway

- This resource is an electronic tool that all practitioners can use, accessing the information and 'sections' of the pathway that are most useful to them in their role.
- Whenever you are supporting a family where somebody has a disability or suffers with ill health, remember to signpost this pathway to all other practitioners (including adult and children's services, and the health, education, and voluntary sectors) who provide support to the same family. They can then access the sections in the pathway relevant to the service they provide.
- Use the **Links** on each page to navigate your way through the information in the pathway. Some links are to other pages in this document, with the page number you will be taken to in the circle next to the link. Others are external, and these sit next to a globe icon. You can also return to the contents page at any point to enter a new section. If you find a broken link within the pathway, please email **include@childrenssociety.org.uk** to let us know.



Introduction: why use the Whole Family Pathway?

The Care Act 2014 and the Children and Families Act 2014 placed duties and powers on local authorities. This means that local authorities must offer an assessment where it appears that a child is involved in providing care. They must consider the needs of young carers if it appears, during an assessment of an adult with care needs or of an adult carer, that a child is providing or is at risk of providing care.

This means children's and adults' services **must** have arrangements in place to assess young carers and make sure no young person's life is unnecessarily restricted because they are providing significant care to an adult.

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

These families may have needs which should be addressed jointly by both adults' and children's services and by all agencies involved in community care (including health, education, and the voluntary sectors).

This is a tool for all adults' and children's services and education, health, and other agencies who have contact with young carers and their families. The Children's Society has developed this Whole Family Pathway to make sure that the same key steps are followed, however a family first makes contact with an agency. The Whole Family Pathway is a resource for all practitioners in every local authority across England.

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

Young carer

- 14) Why do children and young people take on care responsibilities?
- 15 Whole Family Working: the first steps
- 18 When a referral is made for an adult with an illness or disability
- 20 Referral: A child with an illness or disability
- 19 Referral: A child in the family or an identified young carer
- Carers Strategy 2020





The Care Act 2014 requires that children's and adults' services work together to put in place whole family approaches that make sure no care or support package for an adult or sibling relies on excessive or inappropriate caring by a young carer to make it sustainable. This means making sure any assessment takes into account and evaluates how the needs of the person being cared for impacts the needs of the child who is identified as a possible young carer or those of any other child or member of the household.

A thorough assessment centred on the family should result in appropriate support being provided for the person in need of care and support. This may result in the young carer being relieved of part or all of their caring role. Any remaining unmet support needs for the young carer should then be considered and responded to.

To underpin this approach, every local authority should ensure:

- There is a memorandum of understanding between children and adult social services in place that shows how they will work together locally, adopting a whole system, whole council, whole family approach to providing support for young carers and their families.
- There is an active approach to working across systems in partnership with health and with local carers organisations.
- There is ongoing workforce training and development in relation to implementing whole family approaches.

- 8 Definition: 'disabled parent'
- 7 <u>Definition: 'young carer'</u>
- Memorandum of Understanding on working together to support young carers
- Joint strategic needs assessment
- Whole family working





Young carers and their families: definitions and context

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

Young carers: a shared understanding

A young carer is defined in section 96 of the Children and Families Act 2014 as:

'...a person under 18 who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work).'

For the purposes of this document, this relates to care for any family member who is physically or mentally ill, frail, elderly, disabled, or dealing with alcohol or substance misuse.

The key principle is that:

'Children should not undertake inappropriate or excessive caring roles that may have an impact on their development. A young carer becomes vulnerable when their caring role risks impacting upon their emotional or physical wellbeing and their prospects in education and life.'

Care and Support Statutory Guidance. Issued under the Care Act. DH 2014 Paragraph 2.49

- 19 Points to consider on referral of a young carer
- 9 Who do young carers care for?
- Why are children and young people taking on caring responsibilities not identified and reported?
- 14 Types of caring role

- 11) Potential impacts on young carers
- 10 Statistics: young carers in the UK
- Memorandum of Understanding on working together to support young carers





What we mean by disabled parents

The pathway uses the term 'disabled' with the meaning given by section 6 of the Equality Act 2010. A person is a disabled person (someone who has the protected characteristic of disability) if they have a physical and/or mental impairment, which has what the law calls 'a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities'. There is no need for a person to have a medically diagnosed cause for their impairment; the effect of the impairment is what matters, rather than the cause.

It is recognised that not all parents included in this definition would define themselves as disabled people. Parents include prospective parents, biological parents, grandparents, same sex couples, kinship carers, those who raise, adopt or foster children, and step-parents.

Some disabled adults may have support needs related to their parenting roles or responsibilities, and need support to access the same choices and opportunities for themselves and their children as other non-disabled parents.

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

- 18 A parent with an illness or disability
- 41 Nature of illness and disability
- 18) Points to consider on referral

- Translation services
- Why are children and young people taking on caring responsibilities not identified and supported?





Who do young carers care for?

Those cared for may include:

- siblings
- parents, including step-parents
- grandparents
- those who raise, adopt, or foster children
- step-parents.

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

It is important to note that young carers may care for more than one person. Additionally, the cared-for person may not necessarily live in the same household as the young carer. Care may be give to anyone living with:

- physical disability
- sensory disability
- emotional or learning impairment
- long-term illness
- HIV and other blood-borne viruses
- drug or alcohol dependence
- mental health issues
- impacts of war and torture.

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

- 41 Nature of illness and disability
- 26) What to consider when assessing a young carer
- Unaccompanied refugee children





Statistics

Nearly a quarter of a million children in England and Wales are caring for a relative. Figures from the Office for National Statistics (ONS) suggest 244,000 people under 19 are carers – about 23,000 are under nine. This is likely to be 'the tip of the iceberg' and an underrepresentation of the true picture.

Research from BBC and the University of Nottingham in 2018 revealed that 800,000 secondary school-aged young people in England are caring for a parent or sibling.

- 1 in 5 young carers aged 16 to 17 reported a long-term mental health condition (Bennett, L (2019) 'Think data is dull? Get excited by what it's revealing about carers').
- 1 in 4 reported feeling lonely (Department for Education. The lives of young carers in England: Qualitative report to DfE. 2016).
- 40% said they 'never' or 'not often' have someone at school to talk to about being a young carer or young adult carer (Carers Trust, 2022).

- 27% of young carers say that they struggle to balance caring with school or college work (Carers Trust, 2022).
- 52% said they 'never' or 'not often' get help from school or college to balance their work (Carers Trust, 2022).
- As many as 1 in 5 secondary school pupils could be a young carer (BBC News and Nottingham University 2018).
- 40% of young carers and 59% of young adult carers say their mental health is worse since the Covid-19 pandemic (Carers Trust).

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

Young carer



Potential impacts on young carers

Inappropriate caring can impact a young carer's own wellbeing and mean they need support from health and social care services. A whole family approach should be adopted in order to prevent these impacts and protect their wellbeing.

- Young carers may experience problems at school (for example with completing homework or getting qualifications).
- They may be isolated from other children of the same age and other family members.
- They may lack the time for play, leisure, or sport.
- There may be conflict between their own needs and the needs of the person they are helping, leading to feelings of guilt or resentment.
- They may not receive recognition, praise, or respect from others.
- They may feel there is no one there for them or that professionals do not listen to them.
- They may develop physical or emotional health problems themselves as a result of caring.

- They may feel different from other children.
- They may feel that no one else understands their experiences.
- They may have problems moving into adulthood, especially with finding work, living on their own, and establishing relationships.
- Young carers may experience conflicting emotions. For example, they may love the person they care for but resent the burden of care; feel proud of what they do as a carer but dislike the restrictions their responsibilities place on their lives. This may lead to young carers feeling guilty or confused and perhaps being more isolated from their peers.

'It's not just the caring that affects you...
what really gets you is the worry of it all.
Having a parent who is ill and seeing them
in such a state.'

Young carer

- 12 Positive aspects of caring
- 26) What to consider when assessing a young carer
- 39 Education and schools





Positive aspects of caring

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

'Many young carers feel that caring had enabled them to develop a range of practical and useful life skills such as cleaning, cooking and managing finances, as well as an ability to cope with difficult situations and to better understand people. For these young carers, caring had given them an increased sense of independence, competency, and maturity.'

Clay, Connors, Day, Gkiza and Aldridge, 2016

'Helping her is just part of life. I don't really remember it being any different.'

Young carer

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

Young carer





Why are children and young people taking on caring responsibilities not identified and supported?

When there is a person within the family needing care, a child may take on the role of sole or primary carer or may help other adults or siblings with caring tasks. Some choose to take on the task voluntarily, others are informally nominated as a carer, and in some families it is demanded. The majority, however, just grow into the role.

There are many reasons why young carers may remain unidentified and unsupported, taking on levels of care that are inappropriate for their age. These include:

- the nature of the illness or disability, including the speed of onset or whether it is an episodic illness
- fear of the perceived stigma associated with the condition, particularly where there is a mental illness, substance dependency, or HIV
- a lack of effective services from outside the family if the person does not meet eligibility criteria or services are inflexible
- adult and children's services not sharing information or working jointly, or not recognising the need to support young carers until a crisis is reached.

A whole family approach to assessments and service provision is key to identification and support of young carers.

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

Young carer

Links

Whole family working





Types of caring

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

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

'The caring task is something that never stops.'

Young carer

- Why are children and young people taking on caring responsibilities not identified and supported?
- 11 Potential impacts on young carers





Whole family approaches

A whole family approach involves the professionals concerned being able to recognise how the child's wellbeing and development are affected by their caring role. It is also important to understand the extent to which this care is (or will be) relied upon by the family, including the wider family, to maintain the wellbeing of the person being cared for.

Local authority adult and children's services may have overlapping responsibilities in arranging to assess and, if appropriate, support young carers and the person they care for. The primary responsibility for responding to the needs of a young carer rests with the service responsible for assessing the person they support, rather than the age of the carer. This means that:

- Young carers of disabled children are the responsibility of children's services
- Adult services have to identify children in the household or family network to ensure young carers are not left with inappropriate or excessive caring responsibilities.

Links

No wrong doors: working together to support young carers and their families. A template for a local memorandum of understanding between statutory directors for children's services and adult social services, 2015.



Young carers needs assessment





The Care Act 2014 and Children and Families Act 2014 - whole family approaches and the duty to cooperate

The Care Act 2014 introduces a number of reforms to the way that care and support for adults with care needs are met. It requires local authorities to adopt a whole system, whole council, wholefamily approach, coordinating services and support around the person and their family and considering the impact of the care needs of an adult on their family, including children.

The provisions for young carers included in the Care Act 2014 are intended to link with provisions in the Children and Families Act 2014. This is to provide a clear framework for local authorities to take a whole family approach to assessing and supporting adults and young carers and deliver support in a coordinated way.

- A local authority must cooperate with each of its relevant partners and the partners must cooperate with the local authority.
- Local authorities must make sure that education, health, and social care services all work together, if that helps them do better for children and young people with special educational needs or a disability.
- A local authority must cooperate with NHS bodies in relation to the identification of carers.

■ Local authorities should take the lead to engage with a wide range of stakeholders and citizens in order to develop effective approaches to care and support. This should include carers and their representative organisations.

'The intention of the whole family approach is for local authorities to take a holistic view of the person's needs and to identify how the adult's needs for care and support impact on family members or others in their support network.'

Care and Support Statutory Guidance. Issued under the Care Act. DH 2014 Paragraph 6.65

- (Care Act 2014 statutory guidance for implementation)
- Young Carers (Needs Assessments) Regulations 2015





No Wrong Doors: 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, 2015.

This offers a framework which professionals can use to provide personalised and joined up support for young carers and their families.

Its key points on partnership working include:

- Young carers should be identified and assessed, and their families supported in ways that prevent excessive or inappropriate caring and support parenting roles regardless of which service or agency is contacted first.
- NHS England and its partners have developed a toolkit to help health and social care organisations work together to better identify, assess and support young carers and their families. This toolkit includes a template memorandum of understanding that local partners can use to ensure that there is joined up working to support carers of all ages and their families.
- It encourages services to work through the local health and wellbeing board and the joint strategic needs assessment to include identification of the needs of young carers and young adult carers in the local area.

■ The local joint health and wellbeing strategy should include shared strategies for meeting young carers identified needs, setting out arrangements for working together and the actions that each partner will take individually and collectively.

- No wrong doors: working together to support young carers and their families. A template for a local memorandum of understanding between statutory directors for children's services and adult social services, 2015.
- Young carers needs assessment
- Carers toolkit
- 38 Health and care act





Referrals

A parent with an illness or disability

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

- whether there is a child in the family who may be helping to provide care, including extended family members
- whether they have been offered an assessment
- what can be offered to help the whole family
- if the parent needs support in their parenting role
- how to establish routine and coordinated procedures for the early identification of disabled adults with parenting responsibilities, with a view to addressing support needs early and prevent children caring at inappropriate levels
- whether an early help assessment to understand strengths and needs and how best to support the family and young carer
- how to establish an active approach to identifying if there are any significant potential changes in families' lives and work with them to plan for these.

Links



Supporting information for developing local joint protocols between drug and alcohol partnerships and children and family services

36 Early help assessments

Supporting disabled parents and parents with additional support needs





A child in the family or an identified young carer

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

- the amount, nature, and type of care which the young carer provides
- the impact of the caring role on the young carer's wellbeing, education, and personal and emotional development
- whether any of the caring tasks the young carer is performing are excessive or inappropriate having regard to all the circumstances
- whether a needs assessment of the cared-for person (be they a child or adult) has been carried out, and if not, to request one
- whether any of the young carer's needs for support could be met by providing support or services to:
 - the person cared for (by the young carer)
 - another member of the young carer's family
 - what the young carer's needs for support would be likely to be if they were relieved of part or all of their caring role, and whether and whether any of the caring tasks the young carer is performing are excessive or inappropriate given the circumstances.

- 23 <u>Assessments</u>
- 44 Young carers services

- 36 Early help assessments
- Why are children and young people taking on caring responsibilities not identified and supported?





A child with an illness or disability

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

- whether there is another child in the family who may be helping to provide care
- whether the family needs additional support
- what can be offered to help the whole family
- whether the parent needs support in their parenting role
- how Early Help, the Carers (Equal Opportunities) Act 2004, or the Children Act might help you assess and provide support for a young carer or other children in the family
- whether resources from Sibs (the UK charity for brothers and sisters of disabled children and adults) may be beneficial.

- 23 Assessments
- 44 Young carers services
- 36 Early help assessments

- Why are children and young people taking on caring responsibilities not identified and supported?
- Sibs





Consulting with families and service provision

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

- A whole family approach needs to be embedded into local assessments. This means making sure any assessment takes into account and evaluates how the needs of the person being cared for impact on the needs of the child who is identified as a possible young carer, or on any other child or other members of the household.
- Families may need access to independent advocacy to facilitate their involvement in the assessment, planning, and review process.
- Remember it is not good practice to use children or other family members as translators for someone who speaks another language or for someone who uses sign language.
- Remember that a young carer may not necessarily be living with the person they are caring for or may not be directly related to them.
- Use early help assessments to support a team around the family approach.

- Use family group conferences to resolve conflicts of opinion between parents and children as to what is an acceptable level of care.
- Consider cultural perceptions of caring and disability and ask families what would work for them.
- Considering a person's needs within the context in which they live helps recognise what's important to them as part of a family unit as well as individually, and builds on the collective strengths of the family and their support network.
- For families where there are children and young people, plans might include support to help build adults' parenting skills. This includes consideration of support to ensure an adult carer is able to fulfill any parenting role.

- 23 Assessment
- 41 Children as informal interpreters
- Cultural awareness

- Family group conferences
- 36 Early help assessments
- The Care Act and Whole Family Approaches





'The young carers' needs assessment should take into account the strengths of a family, as well as identifying any challenges faced by its members. This involves identifying factors that protect the child from an inappropriate caregiving role alongside their vulnerabilities. Throughout the assessment process, the professional responsible must identify the impact of what is happening in the family on the child.* It is important to separate the child's understanding and their wishes and feelings about the outcome of the assessment from those of the adults in the child's network. The starting point for any assessment will always be – children are children first.'

Young Carers Needs assessment – Supporting information The Children's Socety, ADASS, ADCS, Carers Trust, 2015

* The Young Carers (Needs Assessments) Regulations 2015 - 4(3)

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

Disabled parent

Links



40 <u>Disabled parents with parenting responsibilities</u>





Assessment

The Children and Families Act 2014 amended the Children Act 1989 to make it easier for young carers to get an assessment of their needs and to introduce whole family approaches to assessment and support. Local authorities must offer an assessment where it appears that a child is involved in providing care.*

- All assessments of adults must establish if there are children in the family. This is important so that any parenting responsibilities are taken into account and the impact of the adult's' needs on any child or young person are considered.
- If any child or young person is identified as carrying out a caring role, this should result in an offer of a needs assessment for the adult requiring care and support. The local authority must consider whether to undertake a young carer's needs assessment under the Children Act.
- Under the Children Act, local authorities must assess a young carer on the appearance of need to establish whether they may have needs for support.

- In these circumstances the authority must consider whether the care being provided by the child is excessive or inappropriate, and how their caring responsibilities affect the child's wellbeing, education, and development.
- An assessment should take into account the parenting responsibilities of the person as well as the impact of the adult's needs for care and support on the young carer.
- * Children Act 1989: section 17ZA 1(a) [inserted by section 96 Children and Families Act 2014]

Links

What to consider when assessing a young carer

Young carers needs assessment

No wrong doors: working together to support young carers and their families. A template for a local memorandum of understanding between statutory directors for children's services and adult social services. 2015.





Key principles that underpin practice

Children and adult social services should work together to fulfil duties in law and ensure that the following key principles underpin practice:

- The starting point should be to assess the needs of the adult or child who needs care and support and then see what remaining needs for support a young carer in the family has.
- The presence of a young carer in the family should always constitute an appearance of need and should trigger either an assessment or the offer of an assessment to the person needing care.
- A whole family approach is key when assessing an adult needing care where there are children in the family providing care to the adult or undertaking wider caring responsibilities. The adult's assessment and eligibility for support should take into account their parenting responsibilities and the functioning of the family.
- Assessments should ascertain why a child is caring and what needs to change in order to prevent them from undertaking excessive or inappropriate caring responsibilities which could impact adversely on their wellbeing, education, or social development. It will be good practice to seek the views of children and adults separately, as it may be very difficult for children to say how they really feel in the presence of an adult who may also be the person they care for.
- Consideration must be given to whether a young carer is a 'child in need' under the Children Act 1989.
- The assessment must establish if they are unlikely to achieve or maintain a reasonable standard of health or development without the provision of services and whether their health or development may be impaired if they or their family are not provided with support.

Links

Months No.

No wrong doors: working together to support young carers and their families. A template for a local memorandum of understanding between statutory directors for children's services and adult social services, 2015.





'The local authority must also identify any children who are involved in providing care. The authority may become aware that the child is carrying out a caring role through the assessment of the person needing care or their carer, or informed through family members or a school. Identification of a young carer in the family should result in an offer of a needs assessment for the adult requiring care and support and, where appropriate, the local authority must consider whether the child or young carer should be referred for a young carer's assessment or a needs assessment under the Children Act 1989, or a young carer's assessment under section 63 of the Care Act. Local authorities should ensure that adults' and children's care and support services work together to ensure the assessment is effective – for example by sharing expertise and linking processes.'

Care and Support Statutory Guidance. Issued under the Care Act DH 2014 Paragraph 6.68

Early help assessments can be particularly useful in helping to identify and tackle problems before they become serious and in bringing together a team around the family.

- (36) Early help assessments
- (Care and support statutory guidance)





What to consider when assessing a young carer

It is important to think about:

- the amount, nature and type of care which the young carer provides
- the impact of the caring role on the young carer's wellbeing, education, and personal and emotional development
- whether any of the caring tasks the young carer is performing are excessive or inappropriate having regard to all the circumstances whether a needs assessment of the cared-for person (be they a child or adult) has been carried out, and if not, to request one
- whether any of the young carer's needs for support could be met by providing support or services to:
 - the person cared for (by the young carer)
 - another member of the young carer's family.
- what the young carer's needs for support would be likely to be if they were relieved of part or all of their caring role and whether the young carer has any remaining unmet needs.



Identifying inappropriate caring

When assessing the needs of a young carer, the professional(s) responsible must consider whether any of the caring responsibilities the young carer is undertaking are inappropriate, taking into account the child's own needs. The assessment should take into account the impact of the child's caring role on their health and development. For example, considering:

- whether the child's caring role limits their educational opportunities, perhaps because it means there are reasons why they are absent from school
- whether caring prevents the child from building relationships and friendships
- how caring affects the child's physical and emotional wellbeing.

The assessment must also reach a view about whether any of the child's caring tasks are 'inappropriate', in view of child's personal circumstances. Inappropriate tasks could include:

- personal care such as bathing and toileting
- carrying out strenuous physical tasks such as lifting
- administering medication
- maintaining the family budget
- offering precociously mature emotional support to the adult (for example if the child is effectively 'parenting their parent').

Links

Young carers needs assessment. Supporting information for use in conjunction with No Wrong Doors; template for local memorandum of understanding on work with young carers. 2015





Identifying 'excessive' care

Similarly the assessment must determine whether a young carer is giving 'excessive' care. While a child might carry out relatively minor care tasks within their competence, the time these take up and the demands on the child could place significant limits on their life – for example, if the level of care interferes with school attendance or isolates the child in the home.

The Care Act 2014 also requires that when a local authority is determining whether the tasks a child carries out are inappropriate, it should also take into account the child's own view wherever appropriate.

It is also important to recognise that young carers may have responsibilities for supporting other family members without disabilities such as siblings and this may add significantly to the pressures on them. Any assessment needs to take account of the whole picture and ensure that the overall levels of responsibilities of the young carer are not beyond what is age appropriate.





Young carers in transition to adulthood

The Care Act 2014 (sections 63 and 64) introduces important new obligations to young carers 'in transition' to adulthood. The Act requires councils to undertake an assessment for a young carer if it considers that they are likely to have needs for support after becoming 18 and that the assessment would be of significant benefit to them.

If a local authority decides not to undertake such an assessment it must give reasons for its refusal. Young carers are entitled to an assessment even where the individual they care for (child or adult) does not receive care or support services.

Transition assessments for young carers or adult carers must specifically consider whether the carer:

- is able to care now and after they turn 18
- is willing to care now and will continue to after 18
- works or wishes to do so
- is or wishes to participate in education, training, or recreation.

Specific resources supporting young adult carers into adulthood such as the YAC Pathway tool, Shaping our Future research report, and guide for young adult carers are signposted to below.

- **SCIE: Young carer transition under the Care Act 2014**
- Young adult carers and employment. Dr Joe Sempik and Professor Saul Becker, Carers Trust 2014
- Young adult carers at school: experiences and perceptions of caring and education. Carers Trust 2013
- Improving assessment support for young carers' transition into adulthood





What to do if you identify a 'child in need'

Where a young carer is a 'child in need' needing protection and support or needs early help support, adult workers should discuss the case with the children's services to decide if further action is needed.

Further action might include:

- a referral to an independent young carers' service
- accessing preventative support through the early help network
- a joint assessment where appropriate (there is provision in the Care Act guidance and in Section 17 of the Children Act to combine a young carers' assessment with that of the adult)
- further investigation by children's services about safeguarding concerns if there is a likelihood of significant harm to the child.

Where there are any aspects of a situation that indicates there are concerns about children's and/or vulnerable adults' safety and they require protection from harm these will be responded to swiftly and in line with local safeguarding procedures. Typically, children's services will undertake the provision of services or support to children in need and adult social services will undertake services and support to the adult. These may be directly provided or commissioned from other providers.



Needs assessments for adults

Local authorities must undertake an assessment for any adult with an appearance of need for care and support, regardless of whether or not the local authority thinks the individual has eligible needs or of their financial situation. Wherever an individual expresses a need or any challenges and difficulties they face because of their condition(s), the local authority should ensure that it has established the impact of that on the individual's day-to-day life.

The purpose of an assessment is to identify the person's needs and how these impact on their wellbeing, and the outcomes that the person wishes to achieve in their day to-day life. The assessment will support the determination of whether needs are eligible for care and support from the local authority, and understanding how the provision of care and support may assist the adult in achieving their desired outcomes.

During the assessment, local authorities must consider all of the adult's care and support needs, regardless of any support being provided by a carer. Where the adult has a carer, information on the care that they are providing can be captured during assessment, but it must not influence the eligibility determination. After the eligibility determination has been reached, if the needs are eligible or the local authority otherwise intends to meet them, the care which a carer is providing can be taken into account during the care and support planning stage.

Links

Promoting wellbeing





Whole family approaches to assessment

An assessment must always be appropriate and proportionate to the circumstances of the individual and their family. This means giving consideration to the approach that's likely to allow each individual to express his or her personal views adequately, as well as getting a picture of how these interrelate. Approaches include:

Combining assessments

There can be benefits in combining the assessment of an adult needing care and support with the assessment of another family member or carer, where each individual agrees. Where assessments are combined it is important that each individual has a chance to have a private conversation with the assessor in case there are areas they wish to identify and explore separately. An approach that can be used is 'together, apart, together', where an assessment starts together then works individually with each relevant member and comes back together at the end to look at how the range of identified needs impact on each other or work together.

Integrated assessments

A local authority may join up with another organisation (such as the local authority and NHS or adult social care and children's services) to carry out an assessment provided the person agrees to this. Where there are a number of needs being met by different bodies for different family members it can be helpful to look at how these can be coordinated and linked together to work towards a plan that works for everyone in the family. An integrated approach to assessments can be particularly important at transition.







Promoting wellbeing

Under the Care Act 2014, local authorities have duties to promote the wellbeing of adults with care needs and of their carers. The concept of wellbeing involves taking account of how a wide range of factors will affect how an individual chooses to live their life. These will include their:

- personal dignity (including treatment of the individual with respect)
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control over day-to-day life (including the manner in which they are provided with any care or support)
- participation in work, education, training, or recreation
- social and economic wellbeing
- family relationships and the support offered by their family network
- the suitability of their accommodation
- the support provided by their friendships and social networks.

These factors do not represent a comprehensive list. The relevance of any specific factor will depend on the views, preferences, and wishes of the individual participating in the assessment process.

- Health and social care assessments
- 40 Housing
- Housing adaptation

- 41 Nature of illness and disability
- Family group conference





Responding to the needs of young carers and of the whole family

Some assessments may reach the conclusion that no further action is necessary. More often assessment will lead to the production of a plan describing what support is agreed for the young carer and/or for the person being cared for and the wider family. All plans developed following a young carers needs assessment might helpfully include:

- information about how the child will be helped to thrive outside their caring role (for example, to participate in school, education, or training; to maintain or achieve a good standard of health; to enjoy and achieve, in the same way as other children who do not have caring responsibilities)
- details of any support to be provided to the young carer's parents to build their parenting capacity
- information about local young carers' groups and sources of community advice and assistance.

Plans should only be combined if all parties agree and if combining of plans is in the best interests of all involved. Where one of the plans is for a child, they must have capacity to agree to the combination. If the child lacks capacity, the local authority must be satisfied that a combined plan is in the child's best interests.



Remember

- Where a young carer has been found to be child in need the plan should be assessed at the same intervals as plans for other children in need in the authority.
- A whole family approach to reviews must offer the opportunity for everyone to have their say. It will be important to offer all involved, and in particular children, the opportunity for private conversation, perhaps as part of preparing for a review meeting.
- The review should consider how best to maximise the wellbeing of the whole family, but it will be important that in responding to the needs of the adults concerned sight is not lost of the child's needs.
- The review may need to identify issues where there are differences of opinion between the adults concerned and any young carer or other children. The professional leading the review should aim to reach agreement as to how to resolve these, recognising children's distinct needs and vulnerability and the duty to prevent them from assuming an inappropriate or excessive care role.

■ The review may conclude the plan needs to be revised, perhaps as a result of changes in individual circumstances. The lead professional would then be responsible for identifying the key issues to be re-evaluated, the services necessary to contribute to a revised assessment, and an outline timescale for updating the plan.

- 44 Local young carers services and support
- 41 <u>Nature of illness and disability</u>
- 38 <u>Health services</u>





Early help assessments

'Providing early help is more effective in promoting the welfare of children than reacting later. Early help means providing support as soon as a problem emerges, at any point in a child's life, from the foundation years through to the teenage years.'

Working Together to Safeguard Children, 2015

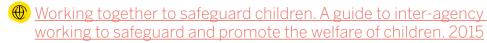
An early help assessment should be used to help practitioners gather and understand information about strengths and needs, based on discussions with the family. The holistic approach to assessment identifies the most appropriate way to meet those needs, and with consent of the family can support information sharing and a team around the family approach.

An early help assessment should be undertaken by a lead professional who should provide support to the child and family, act as an advocate on their behalf and coordinate the delivery of any services. The lead professional role could be undertaken by, for example, a GP, family support worker, teacher, health visitor, or special educational needs coordinator. Decisions about who should be the lead professional should be taken on a case-by-case basis and should be informed by the child and their family.

Links



Information sharing. Advice for practitioners providing safeguarding services to children, young people, parents and carers. July 2018







Think Local Act Personal

Think Local Act Personal (TLAP) is a national partnership of more than 50 organisations committed to transforming health and care through personalisation and communitybased support. The partnership spans:

- central and local government
- the NHS
- the provider sector
- people with care and support needs, carers, and family members.

TLAP works to improve the delivery of personalisation and community-based support and to shape and influence national policy.

Making it Real for young carers was co-produced with young carers and sets out what people who use services and carers expect to see and experience if support services are truly personalised. It explores the six Making it Real themes:

- information and advice having the information I need, when I need it
- active and supportive communities keeping friends,
- family and place
- flexible and integrated support my support, my own way
- workforce my support staff
- risk enablement feeling in control and safe
- personal budgets and self-funding my money.

The document follows these themes and supports them with statements from young carers on what they think needs to be happening, and what they should be experiencing, when an organisation is making good progress towards personalisation.

Links

Making it Real

Making it Real for young carers



Health: the role of health agencies

Health and Care Act 2022

Although social services departments have a key role to play in supporting young carers and their families, they may not always be the key agency for initially identifying needs. Health professionals play an important role in identifying young carers too.

The Health and Care Act 2022 has brought about rights for carers of all ages, including young carers. The legislation outlines the following:

- There is a duty on integrated care boards to consult young carers around planning and commissioning (Section 25).
- There is also a duty to consult young carers around services relating to the patient for prevention, treatment, and diagnosis (Section 25).
- In relation to hospital discharge, there is a duty for NHS trusts to consult with young carers if the person being discharged is 'likely to require care and support following discharge from hospital' (Section 91).

- Supporting young carers and their families: information for health care professionals
- Young carers: a checklist for health professionals
- GPs' information pack

- 15 A whole family approach and joint working
- 41 Nature of illness and disability
- 44) Local young carers services and support
- Health and Care Act 2022





Education

Young carers' suggestions for schools

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

- Make sure there is a clear and up to date community notice board which has support information for us and where else we can get help in the community.
- Ensure teachers are offered training on young carers and disability issues both at university and on inset days.

Young Carers in Schools is a free England-wide initiative that makes it as easy as possible for schools to support young carers and awards good practice.

- Young carers and bullying
- 47 Anti-bullying organisations

- Young Carers Festival
- Young Carers in Schools programme





Housing

An holistic approach to assessment, which aims to bring together all of the person's needs, will include consideration of issues in relation to housing and the impact of this on a person's wellbeing.

The local authorities should take steps to support the individual to access any support to which they might be entitled to in relation to housing and work with the housing authority on related needs. This could include, for example, a referral to the housing authority to access a disabled facilities grant.

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

Disabled parent

- 15 Whole family approach and joint working
- 23 <u>Assessments</u>
- Working together to support disabled parents

- Disabled facilities grant system
- Housing Grants, Construction and Regeneration Act 1996





Nature of illness and disability

Communication needs

It is important that the particular communication requirements of parents are identified so that appropriate support can be provided.

Some people being assessed may have severe communication needs, such as people with profound and multiple learning disabilities, autism, or those who have hearing or vision impairments. It is important to ensure that such individuals have the support of a specialist interpreter to help them to communicate and engage and that children are not expected to interpret for them.

Sign language

The most important step for deaf parents and carers is to let their key worker or lead professional know how they would like to communicate. If they use British Sign Language (BSL), a sign interpreter will be needed for discussions with professionals who do not use BSL.

The Signature website (previously Council for the Advancement of Communication with Deaf People – CACDP) has more information about BSL to English interpreters.

Young carers should not be expected to interpret inappropriate information for their parents, including assessments with a social worker.

Links

SignTranslate

Signature

Deaf/hard of hearing carer's toolkit

Counselling or mental health support for those with sensory impairments

National Deaf Services can provide a range of mental health services

for deaf people.

Minicom: 020 8675 2200

Fax: 020 8675 2266

Email: oldchurch@swlstg-tr.nhs.uk

SignHealth provides a national counselling service delivered in BSL.

SignTranslate will translate more than 300 medical questions into BSL using short video clips.

- Sensory impairments
- British Deaf Association
- SignHealth





Mental ill health

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

Young carers may be responsible for administering medication to parents who have serious mental health problems. This has serious implications for the safety of both the young carer and the parent and must be addressed as a matter of urgency.

Some young carers may be supporting parents who are misusing drugs or dependent on alcohol in addition to having a mental illness.

'No one ever sat down and explained to me and my brother what manic depression was. Mum might have done, but no professional person ... if someone had explained what it was it would have helped.'

Young carer

- Supporting children who have a parent with mental illness
- Information for young carers of parents with mental illness
- SCIE resources: parental mental health and families

- Learning from the experiences of people with mental health problems and their carers
- 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 mental health and substance misuse





Drug and alcohol misuse

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

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

Working Together to Safeguard Children 2018

- Local safeguarding board policies and procedures.
- Interagency protocols for the coordination of assessment and support, particularly across adult drug services and children and young people's services.
- Close collaboration with local diagnostic assessment and treatment services and other agencies that can assist in assessment and outcomes.

Links

<u>Living with an alcohol dependent adult</u>

What about the children?

Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children, 2018





Local young carers' services and support

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

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

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

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

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

- 45 Emotional support and help for young carers
- Memorandum of understanding on working together to understand young carers





Recommendations for supporting the emotional wellbeing of young carers

Information provision

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

Peer support

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

Timely whole family support

■ Work with the family to support them in talking about and coming to terms with illness, if needed. Offering timely, well-structured and flexible support to the person in need of care could prevent a child undertaking inappropriate levels of care.

Coping strategies

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

Working with other agencies

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

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

Links

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



Online resources for young carers and their families

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

Resources for young carers

48 Information about bullying

Website resources for young carers

- Carers Trust
- Being a young carer
- Information for children growing up with a brother or sister who has special needs
- (Childline: Free helpline for children Telephone: 0800 1111
- Help with children's and young peoples' mental health Telephone: 020 7336 8445
- Drug information and advice
 Telephone: 0800 776600
- (m) Information for children affected by a parent's drinking
- (m) The Mix: Support and information for young carers

Resources for families

- Riprap: For when a parent has cancer. An interactive site for children and young people to find out more about cancer and share their experiences with others in their situation.
- <u>Language Line:</u> Language Line Services is a global interpreting and translation company. It enables organisations to communicate effectively with people of all nationalities.

- Citizens Advice Bureau: An online service that provides independent advice on people's rights.
- The Disability Law Service: A national registered charity that provides confidential and free legal advice for disabled adults, their families and carers. This charity also also provides disabled people with a casework service.
- The Equality and Human Rights Commission: The aim of the commission is to end discrimination and harassment of people because of their disability, age, religion or belief, race, gender or sexual orientation.
- Parentline UK: An online resource for support with parenting.
- Ricability: Has produced leaflets on equipment or disabled parents.
- Winston's Wish: An interactive site for young people who have lost someone close.
- Friends, Families and Travellers: Provides information and resources for gypsy and traveller families and those who work with them. The website includes information regarding health entitlements and access to services.
- Medical Foundation for the Care of Victims of Torture:

 Offers free medical, psychological, emotional, and social assistance to survivors of torture and organised violence and to their families. They also campaign against torture and similar human rights abuses.

Cont. on the next page





- Refugee Council Online: The Refugee Council is the largest organisation in the UK working with asylum seekers and refugees. We not only give direct help and support, but also work with asylum seekers and refugees to ensure their needs and concerns are addressed. This website provides multilingual information.
- Refugee Action: Refugee Action has over 20 years experience in the reception, resettlement, development, and integration of asylum seekers and refugees.
- Contact a Family: Helping families care for disabled children.
- **Samaritans:**

Telephone: 116 123

Website: samaritans.org

- (mailting) Talk to Frank: Parental drug and alcohol misuse.
- Mational Star Initiative: Living with an alcohol dependent adult. Telephone: 0800 776600

Bullying

- Anti-Bullying Alliance: The Alliance brings together over 65 organisations into one network with the aim of reducing bullying and creating safer environments in which children and young people can live, grow, play, and learn.
- DirectGov: have information for young people on bullying on their website.
- (## Kidscape: The first charity in the UK established specifically to prevent bullying and child sexual abuse.



The Children's Society's Include service

The Children's Society's Include service supports young carers. Our campaigning and influencing work reaches across the whole of England as we promote best practice and work in partnership with external strategic stakeholders. With our partners, we support young carers and their families and deliver multi-agency, whole family approaches. Our work focuses on the complex needs of young carers who have been identified as exhibiting multiple vulnerabilities and factors of hidden harm, as well as those who are especially hard to reach.







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