

Invisible and in distress: prioritising the mental health of England's young carers

Foreword

Becoming a carer can be daunting at any point in a person's life. Caring can take its toll on health and wellbeing. For young carers coming to terms with caring responsibilities whilst navigating growing up and all that the modern world throws at them can be overwhelming.

The simple proposition of this report is that the well-documented pressures associated with caring should be treated as a risk factor for mental ill-health, especially amongst young carers.

This report draws together what is known about the mental health of young carers. More than that it is informed by the lived experience of young carers. Their voice should be heard and it should shape the response of policy makers, budget holders and service providers.

The right support at the right time can make all the difference. By identifying young carers we can ensure they are not exploited or made ill by their caring responsibilities.

The Rt Hon Professor Paul Burstow
Chair, Tavistock and Portman NHS FT
Minister of State for Care Service 2010-2012

Executive summary

A young carer is someone under 18 who helps look after someone in their family, or a friend, who is ill, disabled or misuses drugs or alcohol. It is estimated that there are up to 700,000 young carers in the UK.¹

Caring roles taken on by children and young people can be a risk factor for their mental health. We know from the 2011 Census that for young carers doing more than 50 hours of care a week they are five times more likely to report that their health is 'not good' and there is evidence that they have significant levels of mental health need that are not being addressed.

This report sets out recommendations based on discussions with young carers, sector leaders and young carers services in the Carers Trust network.

Recommendations include:

- The upcoming Government Carers Strategy should include measures to promote young carers' mental health and improve their access to mental health support.
- The NHS England assurance programme for Local Transformation Plans should examine whether the plans include measures to improve young carers' mental health.
- Local authority commissioners should increase the sustainability and stability of young carers services and support partnership working between young carers services and mental health services.
- National and local government should ensure that they meet their duties to support young carers under the Children and Families Act 2014 and Care Act 2014.

¹ See research from the BBC reported here: <http://www.bbc.co.uk/newsbeat/11758368>

Starting the conversation about young carers' mental health

In national and local policy on children's mental health we find that the needs of young carers are largely invisible. Young carers frequently report that their caring role can cause distress and impact on their mental health. It can cause tiredness, worry, stress and isolation and affect their ability to access services. Whilst a child's caring role can be a positive part of their family relationships and a source of pride it can also be a risk factor for their mental health.

This gap in policy, evidence of need and clear messages from young carers during consultation prompted Carers Trust to start a conversation about young carers' mental health.

Carers Trust held a policy roundtable in November 2015 to discuss the evidence on young carers' mental health and to develop recommendations.

The roundtable was attended by representatives from Carers Trust, Department of Health, Department for Education, Royal College of Psychiatrists, British Psychological Society, NHS England, the Office of the Children's Commissioner for England, The Children's Society, Kidstime Foundation, Sutton Carers Centre and Northamptonshire Carers. The Shadow Minister for Mental Health, Luciana Berger MP, also attended. The discussion was chaired by Rt Hon Prof Paul Burstow and involved two young carers.

Carers Trust would like to thank the young carers and young adult carers who have been involved in this work, as well as the Carers Trust Network Partners that support them and have contributed their expertise.

Message from Emma, a young carer

"From a personal point of view, growing up as a young carer I've had to overcome many different challenges to my peers, in my caring role, which have impacted on my mental health. As a young person who does suffer from mental health problems, and caring for a parent with a range of mental and physical health problems it is something I feel does need change. Better mental health services would definitely be a start as I feel this would benefit young carers especially, particularly when times are tough and when we don't know where to turn to, as this can have drastic problems such as during exams. I definitely want to see a change in the mental health services available for young carers."

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Evidence of mental health needs amongst young carers

Children and young people's mental health can be affected by their caring role, whether the condition of the person they care for is related to physical health, mental health, an addiction or frailty in older age.

The evidence shows that young carers have worse mental health than their peers:

- The 2011 Census found that young carers providing 50+ hours of care a week were up to five times more likely to report their general health as 'Not good'.²
- A survey of 350 young carers found 48% said being a young carer made them feel stressed and 44% said it made them feel tired.³
- A survey of 61 young carers in school found that 38% had mental health problems.⁴

Caring is a risk factor for children and young people's mental health, which continues to be little understood and often invisible to professionals and policy-makers.

Support for the mental health of young carers

The support young carers tell us helps their mental health

Young carers told us about a number of sources of support that they valued because it made a positive difference to their mental health.

- A professional who works with the person they care for taking a whole-family approach and offering them support as a young carer. This may be a health professional, a social worker or someone from another service.
- Counsellors accessed through a young carers service, school, college or their GP
- Emotional support, understanding and flexibility from a teacher at school or college.
- Emotional and practical support from a young carer support worker or peer support at a young carers service.

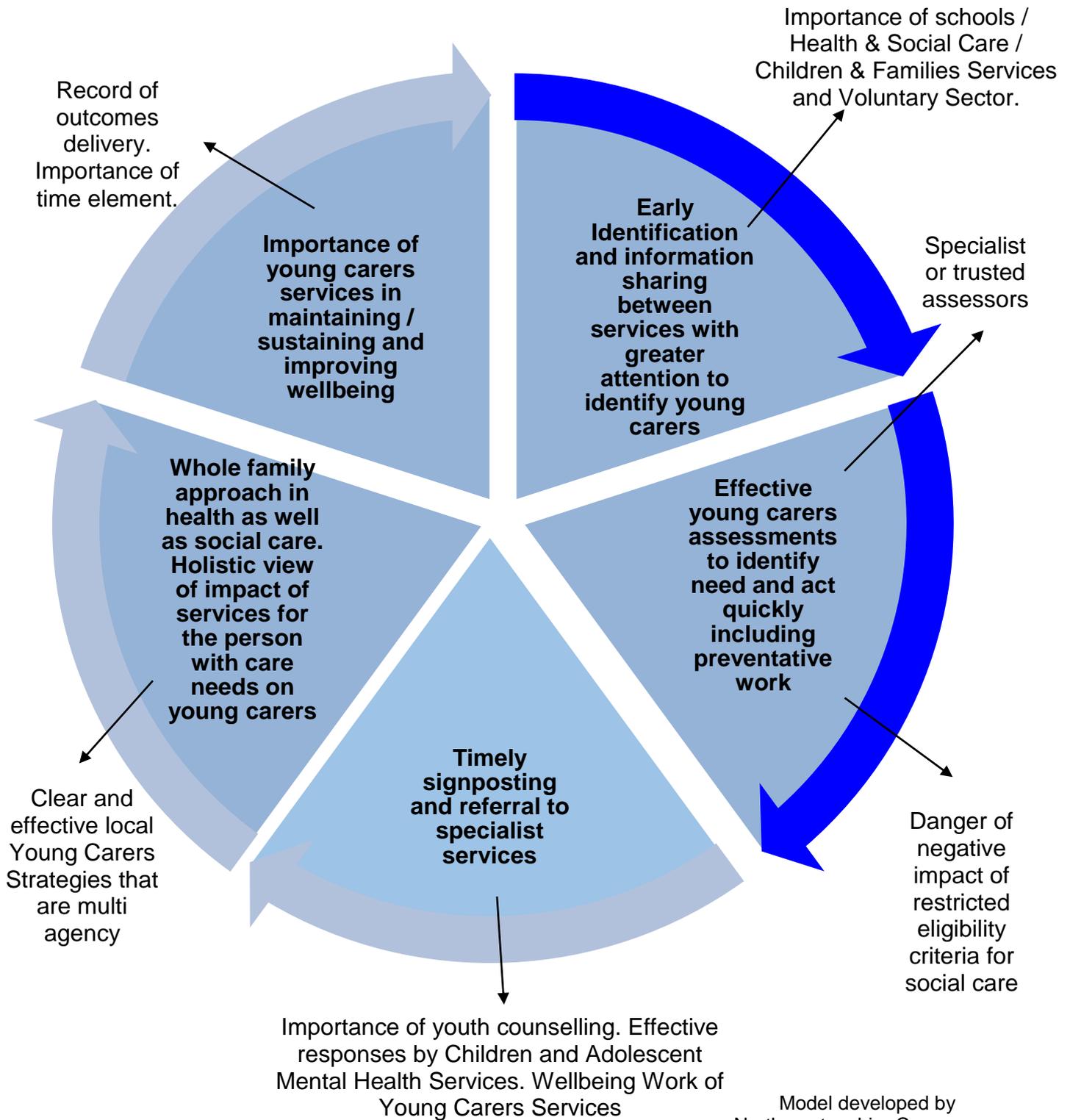
When a whole family approach is used, we can see a "virtuous circle" amongst services that contributes to good mental health amongst young carers. This is described in a model created by Northamptonshire Carers [See Figure 1].

² Office for National Statistics (2013) Providing unpaid care may have an adverse affect on young carers' general health accessed online <http://bit.ly/1uHR1PX>

³ <https://www.carers.org/press-release/research-shows-young-carers-are-worried-and-stressed-proud-what-they-do>

⁴ Sempik, J. and Becker, S. (2013) Young Adult Carers at School: Experiences and Perceptions of Caring and Education. (London, Carers Trust)

Figure 1: Virtuous Circle Model



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Local young carers services play a key role in identifying hidden young carers and making sure that they receive the support they need. These services can struggle to sustain this work, which risks young carers being cut off from support. Commissioning and grant funding of these services is an essential part of ensuring the mental health needs of young carers are considered and responded to.

Barriers that prevent young carers accessing support

Young carers face extra barriers that prevent them from accessing support for their mental health.

The demands of their caring role and their family's circumstances can mean that a young carer will find it difficult to access support because:

- A parent's health condition or disability makes it difficult to accompany them.
- They have to arrange an appointment themselves without the help of a parent.
- There is no one else who can cover the care provision.
- They fear that making their needs known will reveal themselves to be "not good enough" in providing support to their family member, will worry their parent further, or result in they or other family members being removed.

Young carers might need extra support with planning to travel to appointments and to involve their parents where appropriate. Services should offer flexibility about appointment times so they have equal access to services. Specific policies for young carers, information sharing and joint working between services can help overcome these barriers.

Young carers may be more comfortable focussing on the needs of the person or people they care for, not their own health. Professionals should support young carers to consider their own health needs. Young carers need a trusted person to go to so they can raise concerns about their own health and ask for support in a confidential setting or alongside a parent.

Gaps in support for young carers' mental health

Young carers face gaps in support for their mental health that particularly relate to them as young carers. They can struggle to access the right services at the right time, which would address their mental health, their caring role and any relationship between them.

Models of joint working between young carers services and mental health services can improve support for this particular group and involve three key partners.

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Mental health services:

- Access information and training to improve the identification of young carers.
- Reduce practical barriers to young carers accessing their services such as inflexible appointment times.
- Better understanding of caring as a risk factor for mental health.
- Request young carer's needs assessment from the local authority alongside provision of support for their mental health.

Young carer services:

- Improve referral routes for young carers to access mental health services.
- Access advice about supporting young carers with more complex mental health needs.

Local authorities supporting these partnerships:

- Act in line with their duty under the Children and Families Act 2014 to identify young carers.
- Increase referrals for young carer's assessments to identify need.

Young carers report gaps in support that also affect other children and young people. Long waiting lists can leave young carers without support while their mental health needs go unmet. The criteria for accessing Children and Adolescent Mental Health Services (CAMHS) can discourage young carers from getting support so that problems become even harder to tackle and cause more harm. Increasing capacity and access to early support would improve young carers' access to mental health services and their outcomes. Current policies that aims to reduce waiting times and increase young people's access to services should ensure that young carers' needs are also considered.

Recommendations

1. NHS England should issue guidance for services, clinical commissioning groups and commissioners of specialist services on improving young carers' access to services and outcomes.
2. Local authority commissioners should increase the sustainability and stability of young carers services and support partnership working between young carers services and mental health services.
3. Government policies and commissioning guidance on children and young people's mental health should include measures to improve young carers' mental health.

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4. The NHS England assurance programme for Local Transformation Plans should examine whether the plans include measures to improve young carers' mental health.
5. The upcoming Government Carers Strategy should include measures to promote young carers' mental health and improve their access to mental health support.

Early identification and the role of schools and colleges

Young carers should be identified early and not be left to struggle for years before they find out about the support available. Young carers' mental health needs to become more visible to those designing and delivering policies and services in social care, health services, education and many other public services.

NHS services frequently miss opportunities to identify children's caring roles and improve their mental health. They have a significant part to play in making sure that more young carers access support and have a chance to discuss their own health with NHS professionals.

The role of schools and colleges

Schools and colleges are perfectly placed to identify and support young carers, yet we know this is patchy. Better mental health provision in these settings is an important route for young carers to access mental health support within school hours and in a familiar location.

Recommendations

6. Health and care professional bodies should increase awareness of young carers amongst health and care staff so that young carers are identified and are given access to appropriate support.
7. The Department for Education should assist with the development of improved support in schools for young carers, for example, schools' participation in the Young Carers in Schools programme.

Improving understanding of young carers' mental health and what works

Mental health professionals working with children may not be aware of the number who are likely to be young carers. Local commissioners do not have data that would inform the commissioning of good services for this group. By addressing these gaps in our knowledge we lay the foundations for better services for young carers in the future.

At a national level we need to ensure that questions about caring roles are consistently included in government funded research about children's mental health. We also need better evidence on how resources can be used most efficiently to provide the needed support for young carers.

Recommendations

8. The national mental health survey of young people should include questions about caring roles.
9. CAMHS should collect data on whether the children and young people receiving services have a caring role and whether young carers are referred to the local authority for a young carer's assessment.

Caring as a risk factor for children and young people's mental health

Prioritising young carers' mental health in health and social care

For many young carers, their caring role impacts negatively on their mental health. If a family is not receiving adequate support, a young carer may take on a caring role that is excessive or inappropriate. In the long term, addressing the mental health of young carers hinges on the capacity of the health and social care system to offer services to adults and children currently assessed as ineligible for support.

A better funded social care system is needed for the implementation of the whole-family approach set out in the Children and Families Act 2014 and the Care Act 2014. We are concerned that the current settlement restricts implementation of the legislation.

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Increasing the information about support for young carers and their families

Young carers often do not have access to information about the needs of the person they care for. It can make their caring role harder because it is less predictable and further outside of their control. This can cause worry and anxiety. By improving the information given to young carers and creating regular opportunities to talk about their own wellbeing we can improve routes into help and support. Information sharing processes should involve considering what is appropriate for the young carer. These should take into account the wishes and preferences of the young carer, their parents and the person with care needs (when that is not their parent). Other factors should also be considered such as the young carer's age. The Triangle of Care model sets out an effective and widely applied framework of supporting carers, especially within mental health services.⁵

Recommendations

10. National and local government should ensure that they meet their duties to support young carers under the Children and Families Act 2014 and Care Act 2014.
11. All mental health trusts should implement the Triangle of Care for Young Carers and Young Adult Carers to make sure information and support is given to young carers.

Conclusion

This report aims to increase the visibility of young carers' mental health and to recognise the distress that many young carers are experiencing. Caring roles amongst children and young people should be seen as a risk factor for their mental health.

Small changes across schools, colleges, the NHS, social care and other public services would have a significant positive impact on young carers' mental health.

This report recommends that policy-makers, commissioners and professionals prioritise the mental health of young carers. **Better awareness of young carers' needs and specific actions outlined in this report would improve the mental health of young carers now and in the future.**

⁵ Mitchell, A. and Hannan, R (2015) The Triangle of Care for Young Carers and Young Adult Carers: A Guide for Mental Health Professionals (Carers Trust, available online https://professionals.carers.org/sites/default/files/toc_vcyac-proof4.pdf)

Summary of recommendations

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2. Local authority commissioners should increase the sustainability and stability of young carers services and support partnership working between young carers services and mental health services.
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About Carers Trust

Carers Trust is a major new charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

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