Suffolk Carers Needs Assessment: Young Carers and Young Adult Carers Supplementary Report

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Executive Summary

- The identification of young carers and young adult carers can be difficult and often takes place in very different settings to that of the adult unpaid carer population. It also carries with it certain legal rights for the individual and responsibilities for local authorities and CCG partners. For these reasons, this supplementary annex to the full Suffolk Carers Needs Assessment was commissioned to focus solely on the needs of young carers and young adult carers.

- This needs assessment reviews local epidemiological data, existing service provision and available research evidence in order to understand what the needs of the under-25 unpaid carer population are and to establish whether existing services adequately meet this need. Recommendations are then made to stakeholders based on the findings.

- According to the 2011 Census, 1,497 young people aged 0-15 identified themselves as unpaid carers, as did a further 3,216 young carers/young adult carers aged between 16-24. Of these, 495 reported that they were delivering 50 or more hours of unpaid care per week. The majority of young adult carers aged 16-24 years identified through the 2011 Census reside in Ipswich (5.6%) and the lowest proportion resides in Suffolk Coastal (3.2%). When considering young carers aged 0-15 years, the majority again reside in the Ipswich area (2.4%), whereas the smallest proportion resides in Mid-Suffolk (1.5%).

- There is generally a paucity of data on young carers and young adult carers in Suffolk. There is also a large gap between the number of carers identified through the census and those known to services. The profile of young carers is likely to change with the changing demographic in Suffolk. It is therefore important to continue to support ongoing work to improve the identification of young carers and young adult carers. This will not only help build a better picture of the local situation but also provide vital information to inform the commissioning of services to support young carers.
A wide range of services to support young carers and young adult carers exist. It is however difficult to determine, from available data, the exact number and profile of those who access the respective services. It is unlikely that existing services reach all young carers and young adult carers, given that a large number remain unknown to services. Whilst not all those identified need support, demand for services is likely to increase as more young carers and young adult carers are identified.

The findings from the evidence reviewed in this report provide good insight into the needs of young carers and young adult carers. The impact of their caring role on their health, education attainment, employment, personal and social lives is clearly highlighted. The findings and the recommendations from these studies should be carefully considered when designing, commissioning and providing services to support young carers and young adult carers.

Whilst acknowledging that there is already a lot of good working already taking place around the County, the steering group’s recommendations focus around three key themes for ongoing improvement:

1. Improving case finding and identification of young carers and young adult carers across the local health and care system (no wrong doors).
2. Reducing the educational inequalities and inequalities in access to employment opportunities experienced by young and young adult carers.
3. Ensuring young and young adult carers have access to activities and support that will help with common mental health disorders (stress, anxiety, and depression).
Section 1: Background and Introduction

1.1 Background

This report on young carers and young adult carers in Suffolk has been embarked upon as a supplementary annex to the full healthcare needs assessment on unpaid carers, undertaken in October 2014. This needs assessment is about understanding the needs of the under 25 unpaid carer population and establishing whether existing services adequately meet this need.

Young carers and young adult carers are a small but vital cohort within the unpaid caring population. According to data from the 2011 Census, young carers under 15 years and young adult carers aged 16-24 years respectively make up 1.9% and 4.1% of the overall (77,745) population of unpaid carers in Suffolk\(^1\).

These estimates are likely to be conservative, however, due to a number of potential reasons. For example, a lack of awareness among many professional groups of young carers’ needs and concerns and, moreover, young carers’ own lack of awareness of their entitlements, and their reluctance to seek formal help\(^2\).

Identification of young carers and young adult carers can be difficult and often takes place in very different settings to that of the adult unpaid carer population. Furthermore, commissioning care and support services that meet the needs of young carers and young adult carers is quite distinct from that of adults and older people.

It is for these reasons, therefore, that the steering group overseeing the full healthcare needs assessment on unpaid carers felt it necessary to provide a supplementary annex to the main report focused solely on young carers and young adult carers, ensuring their needs were not lost in the breadth of information on adult unpaid carers.

What follows is a condensed needs assessment, focused on the young carer and young adult carer population. It follows a similar systematic approach to that of the full needs assessment, including the descriptive epidemiology, mapping of current service provision,

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stakeholder feedback and evidence of effectiveness/best practice. Through analysing and triangulating the findings from these sections, the steering group put forward three recommendations for Suffolk and sought to align these with the Suffolk Children’s Trust outcomes and priorities framework.

1.2 Introduction

1.2.1 Who Are Young Carers and Young Adult Carers?

No standard definition of the term ‘young carer’ or ‘young adult carer’ could be found in the literature. A desktop review of these terms illuminated a range of broadly similar definitions and age parameters for these two populations.

The Blackwell Encyclopaedia of Social Work\(^3\) defines young carers as:

‘Children or young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would normally be associated with an adult’

Suffolk Family Carers – Suffolk County Council’s strategic partner for delivering young carers and young adult carers services – define access to their young carers services as being for anyone aged 9-15 years and young adult carers services as being for anyone aged 16-24 years. In practice, however, there is flexibility around the upper and lower age thresholds applied, with children as young as 6-7 years presenting and young adult services continuing to offer light touch support to some young adult carers after their 24\(^{th}\) birthday.

Some local authorities and service providers choose to align their service provision more closely with the legal definition of a child and, therefore, define their young carers’ services as being for anyone under the age of 18 years and their young adult carers services as being for people aged 18-24.

The definition and classification of young carers and young adult carers is recognised as being important because it carries with it certain legal rights for the individual and responsibilities for local authorities. The recent introduction of the Children and Families Act

2014 introduces a system of support for young carers and young adult carers which extends from birth to 25, while the Care Act 2014 deals with adult social care for carers over the age of 18. This means the cohort of young adult carers aged 18-25 are entitled to support through both these pieces of legislation. A more detailed explanation of the requirements these two Acts place on local authorities is set out on page 6-7.

1.2.2 Why is it Important for Suffolk?

According to the 2011 Census, 1,497 young people aged 0-15 identified themselves as an unpaid carer, as did a further 3,216 young carers/young adult carers aged between 16-24. Of these, 495 reported that they were delivering 50 or more hours of unpaid care per week\(^1\). However, these figures are likely to be an underrepresentation of need as many young carers come from hidden and marginalised groups, including children caring for family members with mental illness and parental substance dependency. This group of young carers is unlikely to have been captured in the 2011 census data.

There is a growing evidence-base which suggests caring has a significant impact on many young people, especially on their educational outcomes and employment opportunities\(^4\). Support for young carers and young adult carers is, therefore, fundamental to the success of Suffolk’s flagship policies, such as ‘Raising the Bar’ and ‘Suffolk Family Focus’, and key priorities, such as Outcome One of the Suffolk Health & Wellbeing Board ‘ensuring every child in Suffolk has the best start in life’.

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Kelly’s Story – looking after her mum with anxiety issues\(^4\)

‘I live at home with my mum Fiona and younger sister Samantha. Mum has anxiety issues, panic attacks and takes medication for depression.

My job is to reassure her that everything is ok. She gets really anxious and does this horrible routine every night before she goes to bed to make sure everything is switched off and locked. She also switches off each light in the house saying: ‘Off! Off! Off!’ But if her finger slips, she will do it all over again. She’s usually in bed by 9pm after taking her medication for depression, leaving me in charge.

She copes with her anxiety by sleeping during the day as it helps her stop worrying. But it doesn’t stop me worrying. I don’t feel anyone really understands what I have to go through or how anxious I often feel. Looking after my mum and sister is a constant worry and I have to rush home every day after college to make tea, clean and shop’.
Additionally, Suffolk County Council and their CCG partners must work together to respond to important legislative changes relating to young carers and young adult carers set out in the Children and Families Act 2014, Care Act 2014 and NHS England’s recent planning guidance ‘Forward View into Action: planning for 2015/16’:

NHS England’s Forward View into Action: Planning for 2015/16

Engaging Communities

‘First, we expect CCGs alongside local authorities to draw up plans to identify and support carers and, in particular, working with voluntary sector organisations and GP practices, to identify young carers and carers who themselves are over 85, and provide better support. In developing plans, CCGs should be mindful of the significant changes to local authority powers and duties from April 2015 under the Care Act 2014. Plans should focus on supporting young carers and working carers through the provision of accessible services, and services for carers from vulnerable groups. Linked to this, we expect all NHS employers to review in 2015/16 their own flexible working arrangements and support for staff with unpaid caring responsibilities’.

Section 96 of the Children and Families Act requires local authorities to assess whether young carers within their area have support needs and, if so, what those needs are. The right to an assessment of need for support extends to all young carers under the age of 18, regardless of whom they care for, what type of care they provide and how often they provide it. Local authorities must also take reasonable steps to identify the extent to which there are young carers within their area who have needs for support.

With regard to the Care Act 2014, Clause 10 ‘Carers Assessment’ and Clause 12 ‘Family Assessment’ have important implications for local authorities and relevance to young and young adult carers. Carers will, for the first time, have the same rights to an assessment on the appearance of needs as their cared for. For carers, this means that the previous requirement to provide ‘substantial’ and ‘regular’ care will be removed. The whole family will


also be entitled to an assessment. Assessments will need to consider what else (apart from the provision of support) would help to meet desired outcomes. This needs careful consideration so that local authorities do not unduly rely on family (including young and young adult carers) and friends to provide care and support. 

This brief overview of the programmes, policies and legislative framework relevant to young and young adult carers begins to illuminate to readers why, as a Suffolk system, identification and support for this population is a significant issue. The local system cannot expect children to be relied upon to undertake caring which affects negatively their own development, well-being, education and employment opportunities - not only in the here and now, but so much so that it also casts a shadow forward and affects their futures and prospects in later life.

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Section 2: Descriptive Epidemiology

2.1 Prevalence

Prevalence is a measure of the proportion of a population that has a condition at a specific point in time.

We do not know the true number of young and young adult carers in Suffolk as many remain unknown to professionals. In this report, we use the 2011 Census to estimate the number of people who are carers in Suffolk.

The 2011 Census is reported by the Office of National Statistics. This states that there are 4,713 young carers and young adult carers under the age of 25 providing one or more hours of unpaid care per week in Suffolk. 3,216 of these are aged 16-24 years and 1,497 of these are under the age of 16 years.

Young and young adult carers under 25 represent 6.0% of the overall number of unpaid carers in Suffolk (77,745), which is lower than the East of England (6.7%) and England (7.6%) average.

Young carers (0-15) and young adult carers (16-24) represent 1.9% and 4.1% of all unpaid carers respectively. Again, this is slightly lower than the East of England average (2.0% and 4.7% respectively) and the England average (2.1% and 5.6% respectively).

It is worth noting that in 2010, a BBC and University of Nottingham survey of more than 4,000 UK school pupils found one in 12 had moderate or high levels of caring responsibility. This was four times what the official census figures in 2001 showed. This research suggests that the official figures may underrepresent the level of need identified through the 2011 Census. This may be because many young carers often come from hidden and marginalised groups, including children caring for family members with mental illness and parental substance dependency.

2.2 Incidence

Incidence is a measure of new occurrences of a state or condition within a specific time period.

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9 BBC (2010) Young carers are ‘four times’ the official UK number. www.bbc.co.uk/newsbeat/11758368
It is difficult to ascertain exactly how many people become carers for the first time across a time period as this data is not available.

2.3 Place

Place refers to the geographic distribution of the affected population and is an important consideration when determining where to deliver services and projects from. Figure 1 illuminates the majority of young adult carers 16-24 years identified through the 2011 Census reside in Ipswich (5.6%) and the lowest proportion reside in Suffolk Coastal (3.2%). When considering young carers aged 0-15 years, the majority again reside in the Ipswich area (2.4%), whereas the smallest proportion resides in Mid-Suffolk (1.5%).

Figure 1: Percentage of Persons Providing Unpaid Care Aged 0-15 Years and 16-24 Years by Suffolk County Local Authority District (Source: 2011 Census)

Drilling down further, figure 2 below helps to illuminate the percentage of people under 25 providing unpaid care by lower-layer super output area (LSOA) in Suffolk, as reported in the 2011 Census. LSOA areas allow for more accurate comparison between areas because unlike electoral wards, they are composed of a more similar population size (1500 people on
average). The darker shades of green in figure 2 highlight the LSOA areas where there are higher numbers of people under 25 delivering unpaid care. Their distribution across Suffolk varies, although it is important to point out that this does not include a large number of young unpaid carers who still remain unknown.

Figure 2: Percentage of People Aged Under 25 Providing Unpaid Care by Suffolk LSOA

2.4 Time

This section describes changes in the number of unpaid carers between the 2001 and 2011 Census. According to census figures, the number of young people under 25 in Suffolk grew by about 15,000 (from 192,338 in 2001 to 207,447 in 2011). The proportion of people in this age group who identified themselves as providing one or more hours of unpaid care per week also rose from close to 1.8% (3,414 people) in 2001 to about 2.3% (4,713 people) in 2011.

Figure three below shows the absolute (or total) change in numbers of young and young adult carers identified through the census between 2001 and 2011 by district.

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As depicted in the bar graph, the biggest change in the absolute number of carers was in Ipswich, where unpaid carers under 25 increased by 334 (from 708 in 2001 to 1042 in 2011).

However, if we look at figure 4, which depicts the percentage change in the number of unpaid carers under 25 between 2001 and 2011, we see that the greatest increase was in Bury St Edmunds, a change of 51.5% (480 unpaid carers under 25 in 2001 increasing to 727 carers in 2011), followed by Suffolk Coastal and Ipswich.

It is impossible to make definite inferences for the reason behind the increase in numbers of young carers in Suffolk. It could be due to historic under-identification and increased awareness of the need for young carers to identify themselves, therefore leading to better reporting. However, it could also be argued there are higher levels of disability in the overall population, in turn, leading to more young people taking on caring responsibilities.
2.5 Characteristics of the Population Affected

It is important for commissioners and service providers understand the demographic profile of the populations they serve so as to, ensure services are tailored around important characteristics such as age, gender and cultural needs. Figure 5 below helps to build a better picture of the young carer and young adult carer population in Suffolk.
The bar graph shows that the majority of unpaid carers under 25 who self-identified through the 2011 census were female (55.2%), aged 16-24 years (68.2%) and delivered between 1-19 hours of unpaid care per week (76.3%).

2.6 Self-reported health of young carers

Figure 7 below illuminates the vast majority (89.6%) of young carers under 25 years in Suffolk report their health as being ‘very good’ or ‘good’, 8.1% report their health as ‘fair’, and, a small but important minority 2.3% report their health as ‘bad’ or ‘very bad’. However, it is important to highlight that when compared to those providing no care, fewer young carers report themselves as being in “very good or good health” and more young carers report themselves as being in “bad or very bad health”.

Figure 5: Demographics of Young and Young Adult Carers Providing Unpaid Care (taken from 2011 Census).
As has been illustrated in this section, there is generally a paucity of data on young carers and young adult carers in Suffolk. There is also a large gap between the number of carers identified through the census and those known to services. The profile of young carers is likely to change with the changing demographic in Suffolk. It is therefore important to continue to support ongoing work to improve the identification of young carers and young adult carers. This will not only help build a better picture of the local situation but also provide vital information to inform the commissioning of services to support young carers.
Section 3: Existing Services

This section of the report aims to map services and related activities for young and young adult carers aged under 25. In doing so, it aims to address important questions such as:

- Where are services located?
- Are they located in areas where high need is identified?
- What do they provide and when do they provide it?
- Who delivers these services?
- What is the profile of those people using these services?

3.1 Commissioned Services

Specialist support for young carers and young adult carers is commissioned by Children & Young Peoples’ (CYP) Services, Suffolk County Council and provided by the Young Carers and Young Adult Carers projects at Suffolk Family Carers. This involves a range of services namely:

- Information, advice and guidance;
- Group activities and residential programmes;
- One-to-one intervention work;
- Supporting schools to provide a young carer friendly ethos;
- Core support for Young Adult Carers.

3.1.1 Services for young carers (9-15 years)

Services commissioned more specifically for young carers aged 9-15 years include:

- Information, Advice and Guidance – dedicated phone line in the Young Carers Team to answer questions from carers, their families and professionals. Open Monday to Friday, 9am to 4.30pm.

- Communication – regular consultation with young carers via Tumblr and for over 13s via Facebook. Production of a termly newsletter with young carer input.

- Meetings with young carers – yearly assessment/review meetings with all referred young carers who receive a service. Additional one to one meetings with young carers who require extra support.

- Working with the family – working within the Common Assessment Framework (CAF). Attendance at Team Around The Child (TAC) and Child In Need (CIN) meetings advocating for young carers.

- Monthly clubs – 6 monthly clubs run in term-time, based in Lowestoft, Felixstowe, Woodbridge, Bury St Edmunds and Ipswich (2 clubs).
• Short breaks – day events and activities and residential breaks to enable Young Carers to have a break from their caring role.

• Transport – help with transport for those who otherwise could not access short breaks.

• Condition specific work – tailored work with young carers on their ‘cared fors’ condition. This is usually delivered in one to one setting but can be via ad hoc group work where there is need.

• School engagement – working with schools to engage them in carer sensitive practices. Awareness raising, supporting them to adopt good practice within the school, teacher training and encouraging them to work towards the Schools Award.

• Work within school – delivering assemblies, liaising with staff on specific young carer issues, running drop-ins for young carers.

3.1.2 Services for young adult carers (aged 16-24 years)

Services commissioned for this age-group include:

• Information, Advice and Guidance – dedicated phone line in the Young Adult Carers Team to answer questions from carers and professionals. Open Monday to Friday, 9am to 4.30pm. Facebook group for young adult carers to obtain information of events and services.

• Meetings with young adult carers – yearly assessment/review meetings with all referred young adult carers who receive a service. Additional one to one meetings with young adult carers who require extra support.

• Short breaks – day events and activities and residential breaks to enable Young Adult Carers to have a break from their caring role.

• Empowerment and enabling – life skills and other life enhancing experiences (such as support to master independent travel) aimed at empowering young adult carer to lead fuller, independent lives and to engage in their local communities.

• Employment support – support for young adult carers ‘not in education, employment, or training’ (NEETs) and other young adult carers in danger of becoming NEETs with CV writing and interview skills etc.

• Colleges – drop in sessions to provide information, advice to young adult carers.

• Colleges – working with professionals and support for staff to improve young adult carer good practice.
• Condition specific work – working with young adult carers on their ‘cared for’s’ condition.

• Wellbeing Work – Confidence and Self-Esteem courses; healthy eating and first aid courses.

• Mental health pilot work – one off additional funding to support young adult carers who are looking after someone with a mental health condition.

As at November 2014, 1,444 young people had registered with these commissioned services (1,009 young carers and 435 young adult carers). Figure 7 below shows data tracking the numbers of unpaid carers who were registered with the service and those considered to be part of the services active caseload from April 2011 to April 2014. The data shows a positive steady increase in both registered and active cases over the three year period from 2011/12 -2013/14. ‘Active cases’ are individuals currently working with Suffolk Family Carers and receiving a support service, whereas ‘registered cases’ are individuals known to Suffolk Family Carers (who may have previously received a support service) but are not currently in receipt of support.

Whilst this steady growth in the number of cases identified and registered should be commended, it is short of the 4,713 young and young adult carers in Suffolk identified through the 2011 Census, suggesting there may be further to go as a local system in identifying young and young adult carers, and then signposting them to the right support services.

Figure 7: Service Activity Data from Suffolk Family Carers Young and Young Adult Carers Services

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<td>Registered</td>
<td>Active</td>
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<td>Active</td>
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<td>YCs and YACs</td>
<td>638</td>
<td>330</td>
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3.2 Adjunctive Activities

3.2.1 Boost Project

Suffolk Family Carers have raised additional funds to support their work with young carers through external funding bids. Current external funding for young carers has been used by Suffolk Family Carers to commission the ‘Big Lottery BOOST Project’. This project includes events and activities targeting confidence and self-esteem; building peer groups, working in

11 Data with thanks to Kirsten Alderson, Suffolk Family Carers
teams and building confidence. This project has an additional target outcome of reaching rural and BME groups.

Between May 2013 and January 2015, 33 events were held involving 250 young carers. Outcomes included 146 young carers reporting that they had made friends during the activity and 147 young carers reporting improved confidence and developing valuable life skills as a result of the event.

Many young carers have been able to attend residential trips as a result of the BOOST Project, allowing them the opportunity to experience leaving their ‘cared for’ overnight. For the majority, this was the first time they had been away from home. It also gave them the opportunity to improve their self-confidence and self-esteem.

3.2.2 Henry Smith Project

Henry Smith project – funds the Project Manager post in Young Adult Carers Team. In particular this project aims to identify hidden and hard to reach young adult carers, isolated and minority groups. As of January 2015, 305 young and young adult carers from minority groups had been identified by the project.

3.2.3 Pilot Project for the younger (5-8) age group

The 2011 Census identified 1,497 young carers aged 0-15 years. Unfortunately the Census data does not segment the age of these carers further. It is suspected that many young carers under the age of 9 remain hidden from view and uncaptured by the official Census survey.

Suffolk County Council’s strategic partner, Suffolk Family Carers currently supports young carers over the age of 9. Following consultation with parents, Children & Young Peoples’ Services invested £3,000 to enable the Suffolk Family Carers Young Carers Team undertake research and run a pilot session on how best they can respond to the needs of this younger age group.

All of the schools involved in the research have identified a number of young carers and worked well with Suffolk Family Carers to enable early identification. Identification has been facilitated by Suffolk Family Carers who have been actively involved in the schools’ staff CPD (Career Progression & Development) training, assemblies, drop-ins and parent evenings. Suffolk Family Carers are still in the early stages of developing and implementing the respite and support package for this age group and their families.

At the time of writing this report, there was limited information on the impact the intervention has had so far. However, early indications from the evaluation are that primary schools are well placed to identify young carers (5-8 years) and schools have welcomed the opportunity
to participate in the Young Carers Award. Schools participating in the research have identified about 15-20 young carers, demonstrating clear benefits in terms of improving rates of identification. Parents who have had contact with Suffolk Family Carers have also given positive feedback e.g. feeling less isolated and more empowered to seek support. Nurture groups are set to commence in 2016 in all of the schools involved.

### 3.2.4 Young Adult Carer - Mental Health Project

Over 400 Young Adult Carers are registered with the Young Adult Carer Team. Over 40% of these young people are supporting a family member with mental health issues or substance misuse. A significant number of these young adult carers report having issues with their own mental health and wellbeing, and require support with managing stress, anxiety, and poor sleep patterns. The mental health project provides mental health awareness training and subsequently training on different mental health conditions. This allows for the provision of an educational dimension within a supported environment that can help improve the mental health of the young people themselves as well as, indirectly, help them in their caring role.

### 3.2.5 Schools Award

The Schools Award supports schools to develop a young carer friendly ethos with procedures and protocols in place to identify and support young carers. CYP services funds a Schools Lead Worker whose role is to introduce the Schools Award scheme across Suffolk’s schools and academies. Additional funding from CYP has allowed for the recruitment of a part time post to assist the Schools Lead in promoting the scheme and developing a network of school champions across the county to share good practice and promote young carer issues within education.

### 3.2.6 Schools Research Project with University Campus Suffolk (UCS)

Discussions have commenced with UCS to undertake a research project to investigate how the provision of support to young carers in schools might impact positively on attainment, attendance, health and well-being, and confidence levels. The projects fits neatly with the ‘Raising the Bar” agenda, a programme to raise attainment, achievement and aspirations for all young people throughout the County, implementing recommendations from the ‘No School an Island’ report.12

The project aims to identify good practice within schools across Suffolk, including estimates of numbers of young carers and young adult carers; consideration of potential carer related

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12 No School an Island, published by RSA, May 2013
performance indicators for schools; exploration of young carer’s views on the support they currently receive.

The research will examine 3 schools that have not previously engaged with the Schools Award programme and will take a baseline of qualitative and quantities data at the outset, introduce different types of support for young carers to the school, and then examine the impacts and the outcomes (from both soft and hard outcomes) after a school year. The data will inform the strategy for supporting schools in the future and may also help the Young Carers Team to launch a package of support for schools which would help the project to become self-sustaining in the future.

The project is due to conclude at the end of December 2015. Final interview information is currently being collated and a final report is due to be completed by end January 2016.

Overall, a wide range of services to support young carers and young adult carers exist in Suffolk. It is however difficult to determine, from available data, the exact number and profile of those who access the respective services. It is unlikely that existing services reach all young carers and young adult carers, given that a large number remain unknown to services. Whilst not all those identified need support, demand for services is likely to increase as more young carers and young adult carers are identified. The research projects Suffolk Family Carers are embarking on should yield interesting findings that will contribute to shaping future service delivery.
Section 4: Evidence-Base

4.1 Hidden from View

One of the most salient and recent pieces of research that demands further attention is the Children’s Society’s report, ‘Hidden from View: the experience of young carers in England’.

This important study draws on government commissioned data on over 15,000 pupils aged 13 and 14. It examines how many of these children had caring responsibilities, the socio-economic characteristics of their families, young carers’ educational attainment, and their chances of being in training or paid work. The size of the sample should give local service commissioners and policy makers’ confidence in the findings, many of which confirm earlier research.

The Hidden from View report is based on new evidence on young carers from the Longitudinal Survey of Young People in England (LSYPE). The LSYPE was commissioned by the then Department for Children, Schools and Families (DCSF) as a major innovative panel study of young people. It began in 2004, with over 15,000 young people aged 13 and 14 completing questionnaires, and finished in 2010 with over 9000 young people in the original cohort still completing questionnaires.

The LSYPE therefore provides a rich source of information on young people’s lives and their journeys through compulsory education and into adulthood. Of the 15,427 young people who completed the first wave, 689 (4.5%) said yes to the question:

‘Some people your age may have to look after other people. This could be a brother or sister, a relative or someone else who is disabled or sick. Is there anyone like this who lives here with you that you have to look after on a regular basis?’

The LSYPE study provides rich data around young carers’ circumstances, lives and outcomes. The Hidden from View report presents analysis of the data specific to young carers, publically for the first time.

4.1.1 Main findings

The main findings were that:

1. One in 12 young carers is caring for more than 15 hours per week. Around one in 20 miss school because of their caring responsibilities.
2. Young carers are 1.5 times more likely than their peers to be from black, Asian or minority ethnic communities, and are twice as likely to not speak English as their first language.
3. Young carers are 1.5 times more likely than their peers to have a special educational need or a disability.
4. The average annual income for families with a young carer is £5000 less than families who do not have a young carer.
5. There is no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen.
6. Young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers e.g. the difference between nine B’s and nine C’s.
7. Young carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19.

4.1.2 Circumstances Affecting Young Carers’ Daily Lives

The LSYPE data is useful in helping to understand the circumstances affecting the daily lives of young carers. The data has been used to look at household economic factors, parental characteristics, family structure, and young carers’ contact with different agencies. Figure 8 below shows the factors that have a significant and strong association with being a young carer, in comparison with their peers:

Figure 8: Significant and Strong Associations (taken from Hidden from View®)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family income</td>
<td>The median family income for families including a young carer was £5000 less than families without a young carer</td>
</tr>
<tr>
<td>Adults in the household in work</td>
<td>Young carers are over four times more likely to live in a household where no adults are in work</td>
</tr>
<tr>
<td>Maternal education levels</td>
<td>Young carers are 1.6 times more likely to have a mother who has no educational qualifications</td>
</tr>
<tr>
<td>Adults with a limiting disability</td>
<td>Young carers are over twice as likely to live in households where at least one adult has a limiting disability</td>
</tr>
<tr>
<td>Number of children in the family</td>
<td>Young carers are 1.6 times as likely to live in households where there are three or more other children living</td>
</tr>
</tbody>
</table>

4.1.3 Effect on Young Carers’ Education and Employment Outcomes

Missing school because of caring duties is likely to affect longer term education and employment outcomes. For example, within a small group of young carers aged 16-24
years old, a quarter had no GCSEs\textsuperscript{13}. Research has also found that young carers may not reach their educational potential due to the disadvantages they face. This underachievement subsequently affects their teenage and young adult lives, restricting their opportunities and reducing the likelihood of them being students, engaging in further education\textsuperscript{14}, training or employment\textsuperscript{15}.

Analysis of the LSYPE data adds weight to these findings. The average total GCSE points score for a young person who had caring responsibilities in year 9 was 333, compared to 386 for young people who were not young carers in year 9. This is a difference of 53 points, equivalent to nine GCSE grades overall, or the difference between nine B’s and nine C’s\textsuperscript{16}.

The LSYPE data also shows a relationship, although not as strong\textsuperscript{17}, between caring in year 9 and being NEET between 16 and 19 years old. Figure 4 below shows the difference in NEET profiles between the group of young carers and the group of young people without caring responsibilities at those ages. There is a one in three chance that a young carer in year 9 will become NEET between the ages of 16 and 19, compared to a one in four chance for those without caring responsibilities. Figure 9 also shows that the NEET profile for young carers is higher than the national profile.

\textbf{Figure 9 – NEET Profiles for Different Groups within the LYSPE Cohort (taken from Hidden from View\textsuperscript{4})}

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{NEET_Profiles.png}
\end{figure}

\textsuperscript{13} Dearden and Becker (2000) Growing up caring: Vulnerability and transition to adulthood – young carers’ experiences Foundation by the National Youth Agency

\textsuperscript{14} Yeandle and Buckner (2007) Carers, employment and services: Time for a new social contract? Report No.6 University of Leeds and Carers UK

\textsuperscript{15} Frank, Tatum and Tucker (1999), On small shoulders: Learning from Experience of Young Carers

\textsuperscript{16} Significant at the 1% level; non-trivial effect size

\textsuperscript{17} Significant at the 1% level; trivial effect size
4.1.4 Effect on Early Employment

The LSYPE data also shows that young carers in work at age 20/21 are more likely to be in lower skilled occupations, although again this is not as strong as the GCSE link\textsuperscript{18}. Figure 10 below shows that young carers are more likely to be in professions such as personal service, sales or customer service occupations than their peers, and less likely to be in managerial, associate or skilled trade roles than their peers. Young carers are sometimes influenced by the skills gained through their experiences, for example, applying for work in the ‘caring professions’\textsuperscript{19}.

**Figure 10 - Occupations for Young People Who Were in Employment at Age 20/21 for Different Groups within the Cohort**

The LYSPE data demonstrates a significant association between young people caring in their mid-teens and lower educational attainment by the age of 16. There is also a clear association between being a young carer and having lower job prospects and educational opportunities between 16 and 19, and between being a young carer and the likelihood of being in lower skilled occupations at age 20/21. This evidence provides a strong rationale for tackling the problem of young people taking on a caring role during their teenage years\textsuperscript{8}.

\textsuperscript{18} Significant at 10% level; trivial effect size

\textsuperscript{19} Dearden and Becker (2000) Growing up caring: Vulnerability and transition to adulthood – young carers’ experiences

Foundation by the National Youth Agency
4.2 Young Adult Carers at School

Further research that was touched on in the main Carers Needs Assessment and that demands expanding in this supplement is the recent (2013) work of Dr Joe Sempik and Professor Saul Becker. This work was commissioned by the Carers Trust and undertaken by Sempik and Becker under the auspices of the University of Nottingham.

Their research set out to investigate the experiences and aspirations of young adult carers in relation to school, further and higher education and work. A total of 362 people viewed the survey from which the responses of 295 young adult carers aged 14–25 were then analysed.

The first report explored the experiences and perceptions of school by young adult carers who are still at school (n=61).

A summary of the key findings from this research is outlined below:

- A survey of young adult carers (average age 15.5 years) who were still at school shows that two thirds were providing a high or very high level of care.
- Almost a third (29%) reported that their own physical health was ‘just OK’, and 38% reported having a mental health problem.
- Only half had received additional support from a member of staff at school. 42% said there was not a particular person at school who recognised them as a carer and helped them.
- Less than half (46%) thought they had received good careers advice and only 19% of the total sample thought that it took their caring role into account.
- The majority of young adult carers (78%) considered they were doing well at school but less than half (48%) actually said they enjoyed school.
- The majority (84%) said they intended to go to university or college. However, 24% thought they could not afford to go, and 41% were ‘unsure’ whether they could afford it.
- Most (67%) young people informed school staff that they were a carer but the majority of those who did not felt that ‘there was no point’ in telling anyone.
- A quarter (26%) were bullied at school because of their caring role.
- Few (15%) had received a formal review or assessment of their needs, and only half felt that their family received good support and services.
- The majority of respondents who attended a young carers project or a young adult carers project (65%) felt that it had improved their confidence, and 54% thought that they had more friends as a result. 39% felt they had performed better at school because of the project.

21 Sempike and Becker (2013)‘Young Adult Carers at College and University’. London: The Carers Trust
22 Sempik and Becker (2013)‘Young Adult Carers and Employment’ London: The Carers Trust
Based on these findings, the report authors make a number of recommendations, as follows:

**Schools**

1. Schools should establish a clear framework of support for young adult carers, which is embedded into the school’s policies and communicated to parents.

2. Schools should appoint named carer leads to assist young adult carers so that they can achieve their true potential.

3. Schools need better systems in place to identify young adult carers and review the impact of caring on their educational performance and attendance, leading to appropriate personalised support. They should record ‘absence due to caring role’ as a specific category so that data can be collected and statistics can be analysed.

4. There is a need for schools to develop and implement a policy and strategy for dealing with the bullying of young adult carers.

5. Each young adult carer should receive a regular review of their own needs. Appropriate services and support should be provided to ensure that their physical and mental health and wellbeing are maintained so that they can achieve their true potential in all aspects of their lives. Schools should be proactive in ensuring that reviews are conducted and that appropriate action is taken.

**GPs, health and social care**

6. Given the high level of reported mental ill health and other difficulties, GPs, health and social care professionals need to be fully aware of other difficulties related to health or disability faced by some young adult carers. This requires greater identification of young adult carers by GPs and health professionals; and systems to be put in place that enable them to refer on to appropriate services or to provide support directly as appropriate.

7. GPs and other health professionals need to establish systems to identify and assess the healthcare needs of children and young people in families where parents or family members are experiencing ill health or disability.

8. Each young adult carer and their family should receive a regular assessment of their needs and those of the family. Information about assessments should be easily available so that young adult carers know what to ask for, who to ask and what they should receive. Those working with young adult carers should be aware of any statutory requirements and guidance placed upon local authorities to carry out assessments and provide services.

**Young and young adult carer support services**

9. Projects for young carers and young adult carers should seek ways to reduce the amount of care provided by children and young people. This may take the form of helping young people access services and information, facilitating contacts with local authorities and
service providers, and enabling young people to access relevant training to help them in their caring roles. It will also mean working with adult service providers to ensure that disabled and other parents receive adequate support so reducing the need for children and young people to provide care.

Information and advice for young adult carers

10. Careers advice services should be reviewed to ensure that advice adequately addresses and takes account of caring responsibilities.

11. There is a need to provide clear information about the financial support that exists for young adult carers going to college and university. This information should be provided at an early stage so that the young people are able to plan their futures without the uncertainty that currently exists.

12. Services and support for young adult carers should be clearly visible and seen to be effective. Procedures should be in place so that young adult carers know who to tell, how to access services and support, and are aware of the nature of the support they can receive.

13. There is a need to examine the accessibility and usefulness of online support materials for young adult carers and update and improve these as appropriate in order to make them relevant to this group of young people.

4.3 Young Carers at College and University

Young adult carers are often an overlooked group with limited services that meet their needs and little awareness among professionals and the wider public about the challenges they face.

‘Young Carers at College and University’ was the second report published by Sempik and Becker21. In this second report, the experiences and perceptions of 101 young adult carers who are in further and higher education, including those at sixth form college, were explored. A summary of the key findings from this research is included below:

- The 101 young adult carers who were in further or higher education showed that on average they provided a ‘very high’ level of care2.
- 39% rated their physical health as either ‘Just OK’ or ‘Poor’; and 45% reported having mental health problems.
- Despite most respondents (79%) enjoying college or university, over half of them (56%) were experiencing difficulties because of their caring role.
- 16% were concerned that they might have to drop out of college or university. Those who reported that they found college or university difficult had significantly higher caring responsibilities.
- 75% of respondents informed college or university staff of their caring role. Despite this, 45% said there was no one who recognised them as a carer and helped them.
Of those who did not inform college or university staff, the main reason for not doing so was that there was ‘no point’.

- The majority of respondents (62%) had not had a formal assessment by a social worker or other health/social care professional. Almost a third (30%) believed they had not received good services as a young carer or adequate support for their families (31%).
- 56% of respondents received a bursary to help with their studies, including 12 of the 17 at university. Only four respondents (4.6%, n=87) received Carer’s Allowance, and 13 (21%, n=62) were in receipt of some other form of benefit.
- 60 of the respondents were currently attending a young carers or young adult carers service. Of these, almost all (95%) felt that their confidence had improved as a result and that they had more friends (87%).

Based on these findings, the report authors recommended the following:

**Schools and sixth form colleges**

1. Targeted careers advice should be available to young adult carers which addresses their caring responsibilities, recognises any additional skills they have developed in their caring role and supports them to consider all available options.

2. Schools and sixth form colleges should provide a balanced view of courses and subjects and encourage young adult carers to think broadly about their ambitions and aspirations.

**Health and wellbeing**

3. Student health and welfare services need to recognise the physical and mental health needs of young adult carers at college and university and prioritise them for support. They should make explicit the services and support that are available and how they can be accessed. There is a need for ‘joined up’ services that involve both academic and health and welfare services so that support is provided in a holistic fashion.

4. Formal procedures should be available within colleges and universities so that young adult carers can inform staff of their caring roles. Support services should be clearly visible so that young people feel that there is a point in informing staff.

**Study**

5. Colleges and universities should develop policies and procedures that identify young adult carers who are having difficulties with their academic work and provide timely and appropriate support.

6. Colleges and universities should develop awareness training for their staff so that they understand the difficulties faced by young adult carers and know how to identify and support them effectively.
Financial Support

7. Guidance should be developed to help young adult carers who are going to college and university to apply for any bursaries, benefits or financial support for which they are eligible.

4.4 Young Adult Carers and Employment

Young adult carers are often an overlooked group with limited services that meet their needs. There is also little awareness among professionals and the wider public about the challenges they face. In the third report in the series by Sempik and Becker $^{22}$ ‘Young Adult Carers and Employment’, the experiences and perceptions of carers who are in employment, or not in employment, education or training (NEET) (N=77) are explored. A summary of the key findings from this research is included below:

- A survey of 77 young adult carers who had left school and were either in work, or NEET showed that, on average, they provided a ‘very high’ level of care. 27 of the young adult carers (39.1%) who responded did not think that their family were receiving good support and services.
- 45% reported that their own physical health was ‘Just OK’ or ‘Poor’, and over half (51%) reported having a mental health problem.
- Of the 77 respondents, almost half (49.6%) were unemployed. This represents 21% of the total young adult carers in the wider survey who were no longer at school (n=183).
- The most frequently reported highest qualification held by the respondents was GCSEs at grade D–G (28%). Of those respondents no longer in education, only a small percentage (8%) had no qualifications. Qualifications of the rest ranged from GCSEs (49%) through to degrees (12%).
- Of the 37 respondents who answered the question, over half (54%) felt that they would have got better grades at school if it was not for their caring role.
- 87% (of 37 respondents) felt that they had not received good career advice at school; and that the advice did not take into account their caring role.
- Of the 38 respondents who had been to college or university, 11 (29%) had dropped out because of their caring role. This is four times greater than the national average for degree courses.
- Of the 39 respondents who were in work, 17 (44%) had chosen the job because it was not far to travel and they could continue to care; 38% of the young adult carers had also considered flexibility of working hours (so that they could care) when choosing their job.
- On average, young adult carers were absent from work for the equivalent of 17 days per year, and were late or had to leave early on approximately 79 days per year because of their caring responsibilities. This suggests that ongoing caring commitments can have a substantially disruptive effect on workplace attendance.
32 young adult carers in work (67%) informed their managers of their caring role, 41% of these reported that their managers were not supportive.

Only a small proportion of the sample, (6 of the 77 respondents), were in receipt of any benefits. Many more would have an entitlement to some form of financial support but for whatever reason had not claimed, or had not received, any assistance.

Based on these findings, the research authors recommended the following:

**Schools, colleges and training providers**

1. Schools should establish a clear framework of support for young carers, which is embedded into the schools' policies and communicated to parents. There should be a named carers lead within schools and each young adult carer should have an individual plan to address any barriers to education.

2. Targeted career advice should be available to young adult carers which addresses their caring responsibilities, recognises any additional skills they have developed in their caring role and supports them to consider all available options.

3. Young adult carers should be encouraged to identify the transferable skills that they use in their caring roles and to record and develop these so they might use them to their advantage in the workplace.

**Colleges and universities**

4. Early intervention is needed to identify young adult carers at college and university who are in danger of dropping out or not fulfilling their potential, and to provide them with appropriate support in good time.

5. Admissions policies should identify caring roles so that young adult carers can be identified early and support such as flexible deadlines and access to discretionary funding can be provided to enable them to achieve their full academic potential.

**Employers**

6. Businesses should be encouraged to create easily accessible procedures so that young adult carers can inform them, in confidence, of their caring roles.

7. Organisations which support young adult carers have a role to play in drawing up guidelines for this, and in raising awareness among employers.

8. Employers and apprenticeship and traineeship providers should understand the challenges faced by young adult carers and adopt workable policies which clearly define the support and flexibility available to the young adult carers whom they employ.
Assessment and support

9. Young adult carers should be identified early and receive a regular assessment and review of their own needs to ensure that their caring role does not have a negative impact on their education, health and wellbeing.

10. The care and support needs of the person being cared for must be adequately met to enable the young adult carer to participate fully in education, training, and employment so that they achieve their full potential.

11. Young adult carers and their families need high quality information and advice about their entitlements to welfare benefits, and to the health and social care support available to them, including rights to assessments.

12. Health professionals, child and adolescent mental health services, and mental health services need to recognise the mental health needs of young adult carers and prioritise them for support. Young adult carers should be identified as a priority group in key initiatives, for example, in increasing access to psychological therapies.

Carers projects

13. Young adult carers projects should help young people to access the benefits to which they are entitled by providing information and by helping them with the application itself. A guide to the benefits system especially for young adult carers is needed.

Research

14. Further research is needed to explore the relationship between the extent and context of caring and its impact on academic and employment success.

The findings from the studies and reports reviewed in this section provide good insight into the needs of young carers and young adult carers. The impact of their caring role on their health, education attainment, employment, personal and social lives is clearly highlighted. These findings and the recommendations made should be carefully considered when designing, commissioning and providing services to support young carers and young adult carers.
Section 5: Recommendations for Suffolk

This section of the young and young adult carers supplement attempts to bring together the policy context, local epidemiology, review of service mapping and evidence from the available published literature into a concise set of recommendations.

The recommendations have been co-produced with the steering group for this report, which included representatives from Suffolk County Council - Children and Young People’s Services (CYPS) and Adults and Community Services (ACS), and Clinical Commissioning Groups (CCGs), service providers and advocates for young and young adult carers in Suffolk.

Rather than making recommendations that stand in isolation, the steering group have endeavoured to make links with existing work priorities. These recommendations are therefore framed using the Suffolk Children’s Trust priorities for 2014-17, which are:

- Giving every child in Suffolk the best start in life
- Giving every child in Suffolk opportunity to learn and achieve
- Keeping every child in Suffolk safe from harm; and
- Targeting support for children and families who need it most

The steering group’s suggestions focus around three key themes:

1. Improving case finding and identification of young carers and young adult carers across the local health and care system (no wrong doors).
2. Reducing the educational inequalities and inequalities in access to employment opportunities experienced by young and young adult carers.
3. Ensuring young and young adult carers have access to activities and support that will help with common mental health disorders (stress, anxiety, and depression).

These suggestions have been made whilst acknowledging that there is already a lot of good working taking place around these three issues. The following recommendations, therefore, seek build upon rather than duplicate existing work.

Recommendation 1: Improving case finding & early identification (no wrong doors)

Suffolk Children’s Trust Outcome: ‘Targeting support for children and families who need it most’
Focus: ‘Strengthen our multi-agency partnerships to ensure assessment and planning processes are more integrated and robust and that families are at the heart of decision making’.

Local authority commissioners, schools’ senior leaders, Clinical Commissioning Groups (CCGs) and voluntary sector partners should work together to identify ways of increasing case-finding of young carers and young adult carers.
Attention is drawn to some of the marginalised groups highlighted in Hidden from View⁸ where evidence suggests there is a strong association between caring and one or multiples of these factors e.g.:

- Where family members have mental illness or substance misuse dependency
- Minority ethnic communities where English is not a first language
- Low income families and families where no adults are in work
- Families where mother had no educational qualifications
- Households where at least one adult has a limiting disability
- Households where there are three or more other children living

The recent introduction of the Children and Families Act 2014 introduces a system of support for young carers and young adult carers which extend from birth to 25, while the Care Act 2014 deals with adult social care for carers over the age of 18. This means the cohort of young adult carers aged 18-25 are entitled to support through both these pieces of legislation. ACS, CYPs, schools’ and CCG partners must, therefore, work together and in close partnership with health and social care practitioners to ensure the new rights afforded to carers under this legislation are delivered. In practice, this means there can be no ‘wrong doors’ for young carers or young adult carers. Whichever service identifies a young carer or young adult carer in the family, whether it is children’s or adults’ services or the NHS, has the responsibility for referring or assessing the needs of that carer within that family context.

There is a considerable amount of guidance and practice material to help guide local policy and practice on this matter, therefore, this report does not attempt to replicate this.

Recommendation 2: Reducing inequalities in education, attainment and employment

**Suffolk Children's Trust Outcome:** ‘Giving every child in Suffolk the best start in life’ and ‘Giving every child in Suffolk opportunity to learn and achieve’

**Focus:** ‘Early intervention and prevention’ and ‘increase primary and secondary pupils’ understanding of work opportunities and employability skills through further development of the education/employer brokerage and providing an online platform to showcase the economy’

The Longitudinal Study of Young People in England data used in the “Hidden from View” report ⁸ and the work of Dr Sempik and Professor Saul Becker²⁰,²¹,²² both highlight the inequalities in educational attainment and employment prospects experienced by young carers and young adult carers. Sempik and Becker offer a comprehensive set of recommendations aimed at schools and universities that provide a useful baseline to benchmark the local position against.
CYPS currently commission and work in partnership with Suffolk Family Carers through the Schools Awards to help develop a young carer friendly ethos, with procedures and protocols in place to identify and support young carers.

Extending a carer friendly ethos needs to be supported by practical policy changes, in all local secondary schools, colleges and universities in Suffolk. Practical changes to policy would require work with university and college admissions to ensure that their processes identify those with caring roles. Young adult carers could then be identified early and offered support such as flexible deadlines and access to discretionary funding opportunities.

Sempik and Becker suggest that young adult carers should be encouraged to identify the transferable skills that they use in their caring roles and to record and develop these so they might use them to their advantage in the workplace. The local system should work with young carers and young adult carers to help them record and develop the skills, personal qualities and attributes young adult carers have developed in their caring role e.g. empathy, compassion, working in partnership with health and care professionals, taking on responsibility, and a maturity beyond their years, which are transferable to the workplace.

Recommendation 3: Improving young carers mental health, wellbeing and access to positive activities, help and support

**Suffolk Children's Trust Outcome:** ‘Targeting support for children and families who need it most’

**Focus:** ‘Young people have access to positive activities to improve their wellbeing’

Within Sempik and Beckers cohort study, 38% of the young adult carers at school, 45% of young adult carers at college or university, and 51% of the young adult carers in employment reported having a mental health problem when surveyed. We, therefore, echo Sempik and Becker’s recommendations that young adult carers should be identified as a priority group in key initiatives, for example, increasing access to psychological therapies and the need for ‘joined up’ services that involve academic, health and welfare services so that support is provided in an holistic fashion.

Ipswich and East Suffolk and West Suffolk CCGs are re-tendering the Suffolk Wellbeing Service in 2015. The Suffolk Wellbeing Service is an open access (self-referral) service for people experiencing stress, anxiety and depression within a stepped care approach. Currently, access to the service is open to people aged 16+, with some counselling provision available to people 13-15 years of age. As part of the re-tender, the ambition is to extend access to this service to people of all ages. We, therefore, suggest that mental health commissioners work closely with the carers commissioning officers group, as well as wider partners (e.g. school nursing, Suffolk Family Carers etc.), to promote any forthcoming changes to services and to ensure quality signposting into psychological therapies is being targeted at this particular cohort.