



Are Young Carers in Milton Keynes getting the support they need?

Healthwatch Milton Keynes review

March 2018

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1 Who are young carers?

Young carers are children and young people under the age of 18 who provide unpaid care for family members or friends who have a physical or mental illness, disability, or an addiction. There are approximately 700 identified young carers in Milton Keynes, but Carers MK estimate the true number is at least double that figure. These responsibilities can impact on the young person's wellbeing and many young carers struggle to juggle their education and caring role, causing pressure and stress.

2 Why Healthwatch Milton Keynes looked at young carers support?

Healthwatch Milton Keynes received an invitation to bid for funding through NHS England to enable us to run an activity related to Carers. In line with our strategic priorities, and the programme of work we had developed for the year, we decided to use the money to run an activity aimed at reviewing Milton Keynes' achievements against the benchmark standards set in the 'Carers at the Heart of 21st Century Family' green paper. This paper, adopted as a policy document by Milton Keynes Council and by the NHS as a strategy document, has a timeline for implementation of the standards by 2018, and Healthwatch Milton Keynes felt it was timely to ask the young carers of Milton Keynes how effectively MK Council and the NHS have been able to deliver against government aspirations, and what more needs to be done.

Working with our local partners, who specialise in supporting young carers, we engaged with young carers in Milton Keynes to enable and empower them to discuss and share with us their experiences of how their role as a carer impacts on their lives.

We wanted to capture young carers' feedback on whether they felt at any social or academic disadvantage due to their role as carer, and how they had been supported. We also sought to understand the young carers experience of assessment pathways, and whether they, or their parents, could self-refer to support services, as stated in the Children and Families Act 2014.

Healthwatch Milton Keynes asked young carers to tell us about the levels of care they provide in their role. The Care Act 2014 makes it clear that a Local Authority



must protect young carers from providing inappropriate levels of care, such as giving medication and supporting with intimate hygiene, through a statutory needs assessment. This assessment should identify what support the cared for person requires, and establish who should be providing these services, ensuring that the young carer is not being asked to provide care that is deemed to be inappropriate.

We wanted to find out whether young carers received the support they needed, how valuable they find it, and what more could be done to improve support and services to them. We gathered information from a variety of sources to provide a representative sample of evidence of how young people who are carers experience assessment and support services in Milton Keynes and how changes to the Care Act (2014), the Children and Families Act (2014) and the recommendations contained within the 'Carers at the Heart of 21st Century Family' green paper have been experienced by young carers, and what difference this has made to their lives.

3 What do the policy drivers and law say?

As evidence of what works, and as policy drivers for their work with carers, young carers and parent carers, the Milton Keynes Council Joint Strategic Needs Assessment web page lists the following documents:

- Caring for our Future 2012
- The Care Act 2014
- The Children and Families Act 2014
- Carers at the heart of 21st-century families and communities
- The National Carers Strategy

We found that the '*Caring for our Future 2012*' paper which established aims to be realised by 2015, does not refer to young carers, and the '*National Carers Strategy*' is no longer included in the national framework on the Gov.uk website with '*Carers at the heart of 21st-century families*' serving as the main source of policy information for system leaders. Therefore, for the purposes of this report Healthwatch Milton Keynes focused on the legislation and current policy papers affecting young carers directly.

The bulk of the legislation relating specifically to supporting young carers is set out in *The Children and Families Act 2014* with *The Care Act 2014* outlining only the

duty of care that a Local Authority has to young carers and stating that young carers must be given an assessment as they transition to adult services.

The Children and Families Act 2014 states that local authorities in England must provide a young carers' needs assessment if it appears to the local authority that the young carer has need for support, or a young carer or their parent requests an assessment.

This statutory assessment, according to the legislation, must consider whether it is appropriate for the young person to provide, or continue to provide, care for the person cared for. It is not a judgement on the young person's ability to provide care, just on the appropriateness of the type of care needed. The assessment must have regard to the extent the young carer is participating in, or wishes to participate in education, training and/ or recreation. It must also consider the young carer's work or wish to work.

The Care Act 2014 (c. 23) Part 1 – Care and support states that:

- (1) A young carer's assessment must include an assessment of—
 - (a) whether the young carer is able to provide care for the person in question and is likely to continue to be able to do so after becoming 18,
 - (b) whether the young carer is willing to do so and is likely to continue to be willing to do so after becoming 18,
 - (c) the impact on the matters specified in section 1(2) of what the young carer's needs for support are likely to be after the young carer becomes 18,
 - (d) the outcomes that the young carer wishes to achieve in day-to-day life, and
 - (e) whether, and if so to what extent, the provision of support could contribute to the achievement of those outcomes.
- (2) A local authority, in carrying out a young carer's assessment, must have regard to—
 - (a) the extent to which the young carer works or wishes to work (or is likely to wish to do so after becoming 18),
 - (b) the extent to which the young carer is participating in or wishes to participate in education, training or recreation (or is likely to wish to do so after becoming 18).

Both pieces of legislation allow for local authorities to combine the young carer's assessment with that of the person cared for, but only where the young carer and the cared-for person agree. The law also states that the local authority must be carry out the assessment appropriately and proportionately and must provide information about how this will happen, with reasonable notice, before it happens. The local authority can ask another organisation to provide the assessments on their behalf, but no matter who is conducting the assessment, they must be

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appropriately trained and have sufficient knowledge and skill to carry out that assessment.

‘Carers at the Heart of 21st Century Family’ was the strategy released in 2008 setting out the Government’s short-term agenda and long-term vision for the future care and support of carers and said:

“For the many children and young people who support parents or other family members it means making sure that they are not providing unreasonable levels of care, and that they have the support they need to learn, to develop and to thrive.

This strategy sets out the action we plan to take, working with partners and, building on the progress made by our first ever carer’s strategy, *Caring for Carers*, published in 1999.

Responding to the needs of the growing numbers of people who care is one of the major challenges we face as a result of the demographic changes underway today. We must work together using the 10-year framework set out in this strategy to ensure that this challenge is met.” (HM Government, 2008)

This paper states that by 2018:

“children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the *Every Child Matters*¹ outcomes.” (HM Government, 2008)

The ‘*Carers at the heart of the 21st-century family*’ strategy uses young carer experiences to identify the strategy and the priorities to improve care and support for individuals and families. The young carer specific section of the policy says of its vision:

“above all, it is one where prevention - protecting young people from falling into inappropriate caring - is the priority and a guiding principle behind the planning and delivery of services. effective support for families and the person being cared for is at the



heart of this. By 2018, our aim is that all areas will be delivering better joined-up, whole-family support to families affected by illness, disability or substance misuse who have young carers. assessments and support offered will take proper account of the need to protect children from inappropriate caring while families and parents themselves will have a greater say in the shaping of services around them. (HM Government, 2008)

The NHS has committed, through the ‘*Carers at the heart of 21st-century families*’ strategy, to do more to identify carers throughout contacts either with the carer themselves, or through identifying the support needs of the person who needs to be cared for and checking to see how these needs will be met.

4 What does this mean for young carers?

All of these strategies, policies and laws mean that young carers have the right not to be educationally or socially disadvantaged because they are a carer. Young carers have the legal right to request an assessment from the local authority that ensures they are protected from providing inappropriate care. Teachers, health professionals and social workers should be equipped to identify young carers. They can then either refer them to the assessment, or advise the young person, or the person with parental responsibility for that young person on how to request the statutory assessment.

The assessment should consider the young carer’s ability and wishes around providing the level of care that is needed by the looked after person, while ensuring that they are not being asked to do more than they should. The outcome of the assessment should be provided to the young carer and the person with parental responsibility for them and contain information about whether the local authority has found them eligible for support and, if not, why not. The assessment report should also outline what support, if any, the local authority will put in place to remove some of the caring duties from the young carer. The assessment should be free and should not be a judgement on how well the young carer supports the person they care for but, instead, focus on making sure that the young carer is supported well enough that they are not missing out on opportunities that young people of the same age who are not carers are given.



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Our research has identified that, while the Local Authority believes that the pathway to the statutory assessment is in place and adequate, some staff and external referrers (including GPs) find it challenging to navigate the system to organise an assessment for a young carer.

To check the accessibility of the young carers assessment self-referral (young carer or their parent or guardian) pathway, Healthwatch Milton Keynes called Adult Social Care Access Team (ASCAT), which is the only available local authority contact on the Milton Keynes Council young carers webpage. We asked to make a referral for a young carer to be assessed and were advised that ASCAT were not the right team for this. We were put on hold for some minutes before being told that we needed to speak to Childrens Services. The call was put through to the MASH (MultiAgency Safeguarding Hub) who advised they didn't do assessments. When asked who did, we were put on hold again. When they came back on the line, we were told that "because the need is with the adult" it was ASCAT that we needed to speak to. There was no offer to transfer the call, or explanation of why Children's Services didn't carry out assessments for children.

This lack of clarity among staff about who should be carrying out the statutory assessment on this occasion suggests that young carers may find it difficult to access the statutory assessment. Young carers who are unable to access the support and relief from inappropriate levels of caring are put at risk of social, academic and vocational disadvantage.

The Local Government Association has developed a template for a local memorandum of understanding between statutory Directors of Children's and Adult Social Services.¹ The template is called 'No Wrong Doors' and offers a framework for professionals, that local authorities can tailor to the local context, to provide personalised and joined up support for young carers and their families. There is an accompanying document, the Young Carers' Needs Assessments, which outlines the responsibilities of the assessor and the needs that must be considered in a statutory assessment. A link to these papers can be found in appendix B of this report. The adoption of these documents would close gaps caused by any lack of clarity over the pathway to the statutory assessment and who has ownership of it.

¹ LGA No Wrong Doors template - see Appendix B



5 NHS Primary Care and young carers

GP practices across Milton Keynes have prominent physical displays of information about carers, the support available to them and the organisations who can provide this, and many include a link to Carers Direct (an NHS Choices information page). Some surgeries have a reasonably comprehensive carers section on their website which includes a carers identification and referral form. Unfortunately, there are far fewer pages dedicated specifically to, or holding any information for, young carers.

More time with a GP or nurse is something that young carers identified as a need in our online survey and reported that this need was not currently being met. Carers MK are working with GPs to acknowledge work already being undertaken to support carers by local General Practices, support them to refer carers to Carers MK, and provide an accredited framework of good practice to help General Practices develop carer support through the 'Investors in Carers GP Standards' programme.

When Young Carers MK provided us with their referral sources for the first three (3) quarters, we noticed that there had been one referral made to them through a GP and one through Community Health. Healthwatch Milton Keynes sent a letter to all Milton Keynes GP Practices asking if they could tell us how their practice identified young carers, and how they put those identified in touch with the support they are eligible for. The two practices who responded said:

- “forms are available for completion in our reception area & on our website. Also picked up opportunistically during consultations, any new registrations are asked to complete a questionnaire which asks if they are a carer. All identified carers information is sent on to MK Carers for advice/support”
- “Young carers are identified often while the young carer is attending a GP appointment or the person they are caring for advises the GP who is caring for them. We try to encourage adults to recognise that there is a young carer in the family with literature in our waiting room. I am currently in the process of updating our website with information for young carers with the help of Carers MK who I [carers champion] work closely with. Carers MK automatically refers the young carer for a home assessment once they have received the referral from the GP. I have attached the referral form that the GP/clinician completes and the criteria for your information”.



Carers MK have worked hard to raise awareness of the support needs of all carers. However, it appears that they are being identified as the providers of statutory assessments for young carers. The statutory assessment pathway should be clarified and disseminated to health care providers as part of the health and social care integration work that is underway. Healthwatch Milton Keynes would like to see more NHS services actively looking to identify young carers rather than relying on the more opportunistic methods used currently. The 'Investors in Carers' programme may provide GPs and other healthcare providers with new and innovative ways of doing this.

6 Services provided

Young Carers MK is part of the Carers MK charity commissioned by Milton Keynes Council to provide support to young carers. The service provision is made up of:

- a newsletter
- support to access universal services
- invitation to Young Carer clubs
- focused group work
- one-to-one support
- representation at appropriate meetings
- residential respite weekends away

The exact support that each young carer receives will vary depending on the impact their role has on their education, health, wellbeing and social inclusion.

The youth clubs are run weekly by Young Carers MK staff and volunteers and the clubs are split into age groups to ensure appropriate activities for all who attend. This provides one youth club session per month for each age group with the sessions lasting around 2 hours, providing healthy snacks and refreshments, and offering a range of art and craft activities as well as games or sporting activities.

The link to Young Carers MK contained within the Milton Keynes Council Young Carers webpage and the wording used to outline the service implies that a young carer can get the statutory assessment through the Young Carers MK organisation. While Young Carers MK do offer an assessment, it is an assessment of eligibility and level of support that Young Carers MK can provide. They state on their own website that they are unable to take self-referrals, or referrals from parents of the young carer. Their referrals must be made by educational, social care, health or police professionals.

Young Carers MK have told us that while there does not seem to be a clear pathway for them to refer young carers and their families back to the council for the statutory assessment, the local authority has advised them that ASCAT will be able to take the referral and from there, referrals will be allocated to an appropriate team to undertake the assessment.

7 What do young carers say?

To find out how young carers themselves felt about the support they were offered in Milton Keynes, we attended a number of youth clubs run by Young Carers MK. We also ran an online survey which we distributed through local schools, parish councils and our voluntary and community sector partners, the MK Council public health team's Healthy Young Persons Network and the media. The survey was designed to be anonymous to encourage input from young people who either don't wish their situation to be public knowledge, or those who may not identify what they do as being a 'carer'.

The most concerning theme that emerged, both in conversation and through our survey, was how many young people were providing what the government has classed as inappropriate care. This includes bathing, toileting, giving medication, or watching over someone who has had too much alcohol or taken dangerous drugs. While cooking and cleaning was a standard task for most of the young carers, as with many young people who don't have caring roles within their families, when this encroaches on their school or social life from their early teens, it may be something that a statutory assessment could highlight as being inappropriate.

As the club offers a vital opportunity for these young carers to relax, unwind and enjoy the company of others in similar situations, it would have been both obtrusive and inappropriate to attempt the structured interviews we had originally planned to conduct. Instead we used the opportunity to chat informally with groups and individuals to begin to form a picture of their experience and concerns.

We discovered that there was a fairly even distribution between young people caring for family members who had a physical illness or disability and those who were caring for someone who had mental ill health or addiction issues. Many of the young people we spoke to had more than one family member with care needs and a smaller number were caring for someone with complex social problems.

We found that even though these young people were identified as young carers, very few of them felt they were doing anything out of the ordinary. They saw the duties they carried out for family members as just what families do for each other.



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The danger for young carers in this thinking is that, as they grow older and their caring role increases, they may feel that they cannot, or should not, go on to further education, training or work outside of being a carer.

One of the young carers we spoke to at the 8 to 10 year old club session told us they were disappointed that they were not allowed to bathe or dress their family member yet as they were deemed to be too young. While we were pleased that this young carer had been protected from providing inappropriate care, it highlighted to us the responsibility these children assumed, in part due to the maturity expected of them in their situation.

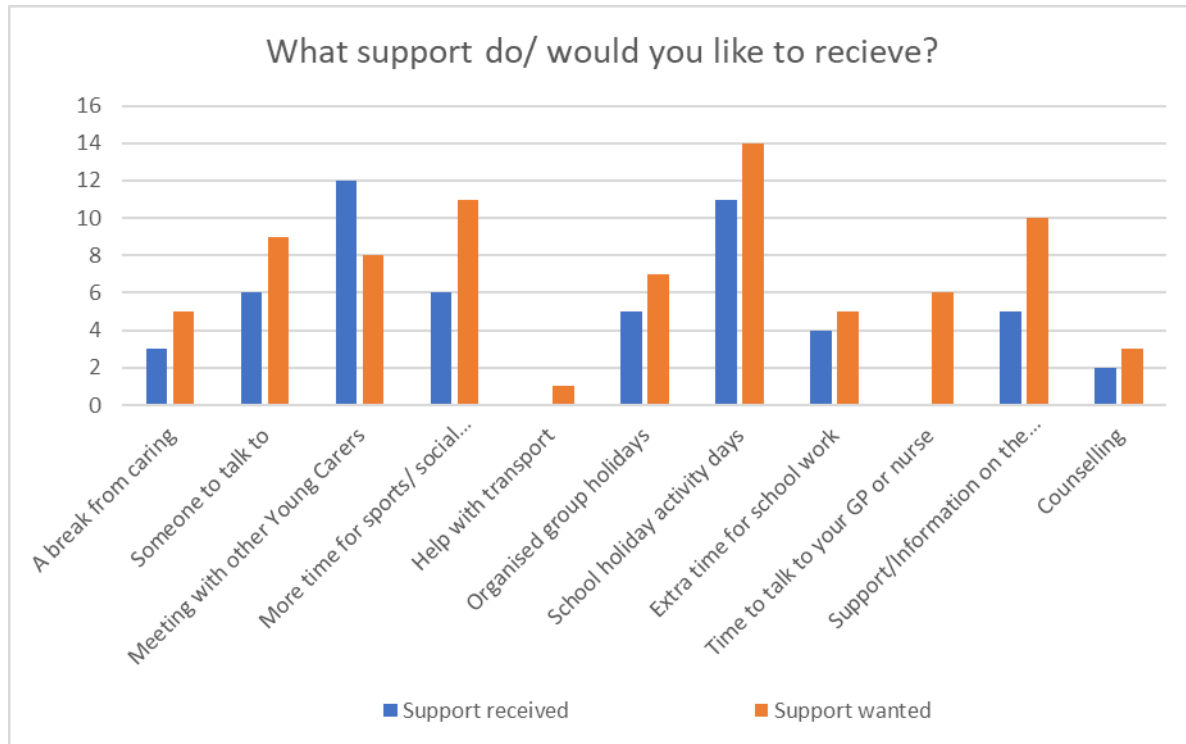
All of the young people at the youth clubs have been identified by Young Carers MK as being eligible for support through their organisation and those we spoke to were very appreciative of the one-to-one support and the opportunities that the youth clubs provided to them. All of the young carers we spoke to at the clubs said that their schools were aware of their caring roles and were supportive.

The survey results showed a mixed experience of support. This could be because those filling in the anonymous online survey are less likely to engage with support available because of their desire to keep their situation private as opposed to those young people already actively involved with organisations like Young Carers MK. Those young carers wishing to keep their situation quiet, have no clear self-referral pathway into the Local Authority for a statutory assessment. This means their only option is to confide in a teacher, health professional, social worker or police officer to refer them in to Young Carers MK to receive social and emotional support. Because there may be tensions between the cared-for person and these organisations, there can be a barrier created that prevents the young person from asking these authority figures for help.

Nearly half of the respondents to our online survey reported that they had not had an assessment because they didn't know how to get one. As most of the young people who reported not knowing how to access assessments have been providing care for over five (5) years, it highlights the need for a clear and widely disseminated pathway into a Local Authority assessment.

The survey asked respondents to identify the support they currently received and what support they would like to be able to access. Comparing the support available to what young carers would like to receive highlighted the gaps in provision, and the areas most in need of improvement:





While our survey shows that none of our respondents were currently given time to speak with their doctor or nurse, six (6) reported that it was something that they would like to see made available to them. Similarly, while five (5) young carers said that they were given information and support around the condition of the person they were caring for, ten (10) more said they would like to have this made available to them.

One young carer reported that they had not received any of the support available but did not elaborate on why this might be.

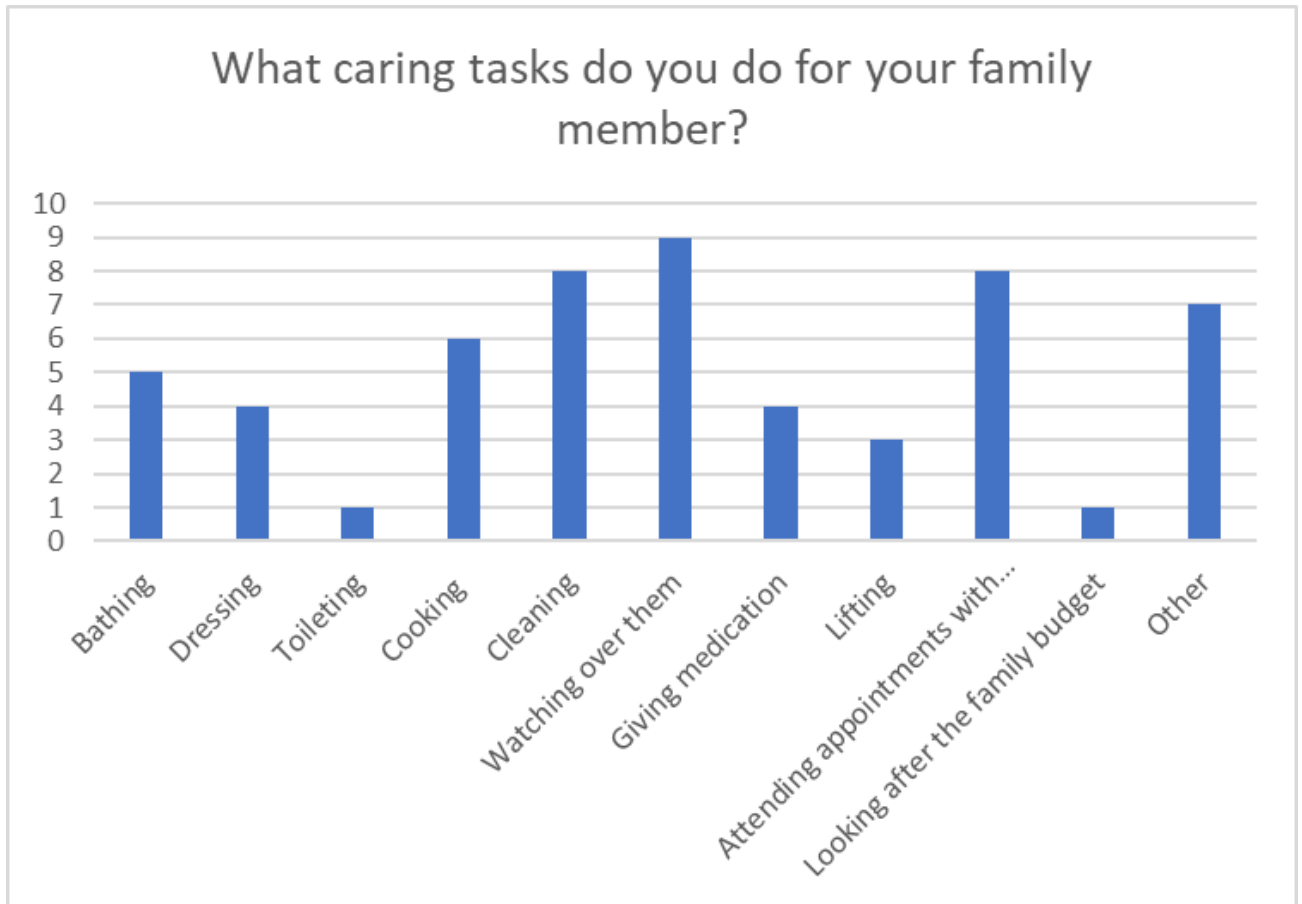
Two (2) young carers reported that they were receiving counselling but three (3) more reported this was a support they would like to access.

Ten (10) of the young carers who responded to our survey have been caring for their family member for more than five (5) years with three (3) reporting that they have been providing care for between 1 and 5 years with the remainder having been carrying out caring tasks for less than a year. With seven young carers providing care for approximately 10 hours per week, seven (7) providing between 20-30 hours care and three (3) providing more than 30 hours care per week, on top of their schooling, it is highly likely that these young people are being socially and academically disadvantaged.

Our online survey asked respondents to identify what types of care they provided to the family member they cared for. The results from our survey, and the conversations with young carers at the youth clubs show that many young carers in Milton Keynes are providing care at a level that the law says they should be protected from. The graph below shows the responses from the online survey:



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Young carers are carrying out this care against what the government has legislated, and from the feedback we received during our conversations, there may be some resistance to relinquishing these duties to ‘outside’ help. The Local Authority may need to invest time to allow their staff to build trust with young carers. and prevent potential barriers to entrusting the care of a close family member to a stranger who the young carer may feel isn’t invested in the wellbeing of the family.



8 Conclusion

At the time of writing this report, frontline staff appear to be unaware of the pathway to the young carers statutory assessment that the directors and commissioners believe is in place which effectively means there is no clear pathway. The information on the Milton Keynes Council website mainly focusses on adult carers and those who need care, with contact details for these services readily available.

The Milton Keynes Council young carer's webpage² outlines some of the caring tasks that young carers may provide which may help a young person to clarify that they may be recognised as being a carer. However, the tasks described are of the type that legislation has said could be inappropriate for a young person to provide. The page goes on to state that young carers may miss out on things like school, sports and hobbies without explaining that the young person is protected by law from these types of tasks or missed opportunities. The page goes on to suggest that Young Carers MK could provide support but does not mention the duty of care that the council has to ensure the young carer is supported. It would be more appropriate for the webpage to make it clear that, if a young person is providing this level of care, or if they are missing out on schooling or a social life, they are entitled to a statutory assessment. The webpage should also provide a direct pathway to requesting a statutory assessment.

The onus of caring for young carers falls, by default, to Young Carers MK who are unable to provide relief from inappropriate care, although they are working with schools to ensure that young carers are not disadvantaged or penalised for having such heavy extracurricular responsibilities.

² Milton Keynes Council Young Carers Webpage - See Appendix B



9 Recommendations

1. Healthwatch Milton Keynes commends those GP practices who have begun working with Carers MK to gain the 'Investors in Carers' accreditation. We firmly believe that this training would enable the NHS to achieve the goals it has set for Primary Care to better look after the nation's carers. We recommend that all GP practices sign up to the standard.
2. We encourage policy makers to take advantage of the Local Government Association assessment templates and supporting information to ensure that Milton Keynes provide its support to its young carers consistent with The Young Carers (Needs Assessments) Regulations 2015 .
3. We recommend that a review of the current pathway to assessment is undertaken to ensure that any gaps in provision are remedied and that young carers and their parents have a mechanism to be able to self-refer to the statutory assessment
4. Healthwatch Milton Keynes would like to see that all local organisations with webpages focussed on young carers are unambiguous about what a young carer can expect from their role, and what they should be protected from. The websites should also contain a clear and direct pathway to requesting a statutory assessment.



10 Appendix A: Local Government Association documents

The template: *No Wrong Doors: working together to support young carers and their families* can be found at

<https://www.local.gov.uk/sites/default/files/documents/no-wrong-doors-working-to-27d.pdf>

The *Young Carers Needs Assessment supporting information* can be found at

<https://www.local.gov.uk/sites/default/files/documents/Young%20Carers%20needs%20assessment.pdf>



11 Appendix B: Milton Keynes Council Young Carers Webpage

Webpage (copied below for ease of reference) can be found at
<https://www.milton-keynes.gov.uk/social-care-and-health/adult-social-care/carers-support/young-carers>

Young Carers

A 'young carer' is any child or young person who is looking after somebody who has a long term illness, a physical disability or a mental health problem. If you're a 'young carer' you'll probably spend a lot of time doing things for other people, (Milton Keynes Council) usually in your family, who cannot do those things for themselves. Examples of the things young carers do include helping someone to eat or bath, giving someone their medicine or keeping an eye on someone if they drink too much alcohol or take dangerous drugs. Some young carers may be helping people who behave oddly at times or have mood swings. .

Sometimes 'young carers' miss out on important things like school, sports, hobbies and socialising because they're so busy helping out or they are worried about the person they look after.

It is important that young carers and the people [sic] that they look after get the help and advice that they need.

Young Carers MK is a specialist service to support young carers living in Milton Keynes. Young Carers MK can help to make sure the person that is being looked after gets the help they need from the council, it also can help the young carer by offering support and activities including:

a chance to talk to someone about your situation

youth clubs, trips out and social events



Service Provider Responses:

Milton Keynes Clinical Commissioning Group



Milton Keynes
Clinical Commissioning Group

18 July 2018

Tracy Keech
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Dear Tracey

Thank you for your report titled "Are Young Carers in Milton Keynes getting the support they need" we have shared this report with commissioners within the CCG for comment. We would like to thank Healthwatch for producing this report on such an important issue. We will consider the findings and recommendations in how we commission new and existing care.

We will work and support GP practices to gain the "Investors in Carers" accreditation and will promote and recommend that practices sign up to the standard during our practice visit programme, this will include information for young carers that be included within their websites.

We will be sharing your report with our practices once it is published on your website.

Once again thank you for undertaking this report and we look forward to working with our practices to commence work on the issues that have arisen.

Yours sincerely

Matthew Webb
Chief Officer



Milton Keynes Council

We have noted the content of the report and will review our services in light of the recommendations. We thank Healthwatch for the report and hope in the future we can work in partnership to improve service for the people in Milton Keynes.

Victoria Collins

Service Director, Adult Services

People Directorate, Milton Keynes Council

Carers Milton Keynes

I have discussed the report with representatives of Milton Keynes Council responsible for young carers and Carers MK will as a result of the information in the report be reviewing our web offer to local young carers. I am the person who will respond to you with the actions we have taken following the review.

Stephen Archibald

Chief Executive

Carers Bucks & Carers Milton Keynes

