

Carers in Hertfordshire

Response to Hertfordshire County Council's consultation on proposals to increase charges for community-based adult social care services (Oct – Dec 2017).



1	<p>This consultation has caused considerable alarm and distress to carers evidenced by:</p> <ul style="list-style-type: none">• the number of individual carers (more than 50) who contacted Carers in Hertfordshire to express their concern about it;• discussions in our Carers Hubs which led two Hubs (Stevenage and Hemel Hempstead) to approach Carers in Hertfordshire to ask that we organise a consultation/discussion session for a wider group of carers and that we submit a collective response on their behalf.
2	<p>Carers in Hertfordshire's response to these contacts has been to advise carers to respond to the consultation explaining the impact that any increase in charges would have on them and on the person they care for and to organise a consultation/discussion session on Carers Rights Day, 24 November 2017, which was attended by Iain MacBeath, Director Adult Care Services, with Lynn Quick and Simon Rowley, Income Team.</p>
3	<p>As a collective response on behalf of carers across the county, Carers in Hertfordshire comments on the proposals as follows:</p>
a	<p>We are concerned to note that these proposals appear to affect the most severely disabled people who are being supported to live in their own homes, either alone or with family – spouse/parents. This is evident in that the increased charges would be borne by:</p> <ul style="list-style-type: none">• those receiving the higher rates of Disability Living Allowance (DLA)/Attendance Allowance (AA)• those who need more than one care worker to attend to their needs, possibly either for hoisting or because of behaviour related issues

	<ul style="list-style-type: none"> • those living in Flexi-care accommodation • those who use transport to attend a Day Service • those who have been provided with a Telecare alarm – usually those who live alone or who are alone for reasonably long periods. <p>We consider therefore that these increases will disproportionately affect people with more severe disabilities and higher levels of dependency and that this is an Equalities issue which was not satisfactorily addressed in the Equalities Impact Assessment published on the consultation page on the Herts Direct website.</p>
b	<p>Universal Credit is now being rolled out and the advice from that national Citizens' Advice Bureaux is that disabled people are among the key groups that are likely to lose out under Welfare Reform. This will particularly affect severely disabled people who live alone – for example in supported living accommodation – who are likely to lose £28.00 - £58.00 each week. Whilst existing claimants will not lose out immediately as their current levels of benefit will be protected at point of transfer to Universal Credit, they will have their level of benefit frozen with no increases to take account of rising prices. They may also see their benefits cut immediately if their household circumstances change. New claimants will be affected by this cut immediately.</p> <p><i>Disability Rights UK has commented, The Government estimates that about 2.8 million households will gain financially from the changes, and about two million households will lose out. Whilst some disabled people will gain from the new system, many disabled people will get very significantly less help because some of the additional support in the current system will not be provided to the same degree in universal credit. We are very concerned that the scale of the cuts in support for some groups of disabled people has not yet been properly understood, because the changes have been viewed in isolation. (Disability and Universal Credit, July 2011).</i></p> <p>It should be noted that the gainers are likely to be disabled people in employment and not those who rely entirely on</p>

	<p>welfare benefits.</p> <p>Given that the transfer to Universal Credit will mean that disabled people will have less available income, it seems inappropriate for the County Council to propose increasing charges at this time when they would have to be re-assessed and reduced in the future.</p>
c	<p>We note that the rationale for taking into account the difference between the higher rate and middle rate of the care component of DLA and the higher rate and lower rate of the care component of AA when assessing income is to bring this into line with the way in which the County Council assesses the income of people who receive the Personal Independence Payment (PIP). In the latter case the full PIP daily living allowance, whether at the standard or enhanced rate is taken into account. However, in order to be eligible for the higher rate care components of DLA and AA, people have to demonstrate that they need help and supervision throughout both day and night, or that they are terminally ill. In the case of PIP there is no eligibility requirement to demonstrate the need for assistance throughout the night – the Department of Work and Pensions decides whether someone is eligible for standard or enhanced rate PIP on the basis of the level of extra help and support they need with daily living.</p> <p>We therefore consider that unless the social care service provided includes support throughout the night the current system, where the difference between higher and middle/lower rates is disregarded, should continue. The proposal would otherwise involve including an allowance which is intended to cover care needs throughout the day and night in an assessment for daytime care only. This consideration is particularly relevant where family – parents or spouses are providing any support needed during the night.</p> <p>We also consider that it would have been appropriate to align the PIP assessments with the approach to DLA and AA assessments and disregard the difference between the standard and enhanced rates. This is because it is likely that the enhanced rate is being paid to those with more</p>

	<p>severe disabilities who may well need support with care needs at night. We believe that the failure to acknowledge this simply disregards the support that many family carers are providing, particularly at night. 53% of carers who responded to the Hertfordshire State of Caring survey, 2015, said that they had trouble sleeping at night because of their caring role. Whilst this can be a side effect of stress, carers of people with Dementia often report having to wake at night when their spouse/parent gets up and wanders about the house. Similarly carers of people with disabilities may have to be alert at night in case of epileptic seizures or support with toileting. One carer reported frequently getting up during the night because an adult son with autism spectrum and learning disabilities would wake and shower in the early hours of the morning and needed some supervision in order to stay safe.</p>
d	<p>In relation to the proposal to charge the full cost of ‘double handed’ care, we note that two care workers are generally required for hoisting for personal care, bathing, toileting, transferring to and from bed/chair. Two might also be required where the service user displays difficult or challenging behaviour. In both situations the service user has no choice but to use this level of service if they are to remain safely in their own homes. The alternatives would be admission to residential care where more staff are on hand as needed or a heavier role for the family carer if available.</p> <p>We therefore object to this proposal – as particularly discriminatory towards the most disabled people and likely to discourage people from remaining in their own homes.</p>
e	<p>We understand that Flexi-care accommodation includes Extra-care housing and Supported Living. Extra-care housing was developed to provide a cost effective alternative to residential care for older and physically disabled people whose care support needs can be more easily managed where there is access to 24 hour support as and when needed. We note the current level of charges for each of the three bands, which seem very reasonable. There does not appear to be any explanation or rationale</p>

	<p>for increasing these charges beyond increasing income. This does not take account of the strong possibility that people would be discouraged from moving into Extra-care housing by the proposed level of charging.</p> <p>The County Council might consider introducing more bands so that charges related more closely to the level or hours of support required.</p> <p>Most people who are accommodated in Supported Living are in receipt of Benefits and our comments on increasing charges for those groups are included in 4 (b) below.</p>
f	<p>Increasing the journey to and from the Day Service by £1.00 per journey does not, on first consideration, appear unreasonable. However this would mean an extra £2.00 per day, possibly £6.00 or more per week to people whose sole income may well be welfare benefits. This would certainly be the case for most people with learning disabilities.</p> <p>It may be that transport to LD Day Services has become more of an issue since the closure of the smaller local Hubs, however Adult Care Services might consider investing in more travel training for those who could learn to travel independently to a known venue as a means of offsetting some of the costs and promoting independence.</p>
g	<p>We acknowledge that it does not seem unreasonable to have the same charge for Telecare alarms irrespective of whether they are provided by Serco or Careline. We would, however, note that these personal alarms linked to a call centre, were introduced to enable elderly frail people to live alone more safely and to reassure their relatives that there was a safety net if they were suddenly unwell or in difficulties. We would be concerned if the introduction of charges to those currently receiving a service from Serco discouraged their on-going use or take-up. We would expect such charges to be included in Disability Related Expenditure and we have some concerns about the telephone call charges involved.</p>

4	Carers in Hertfordshire also wishes to make the following comments, following discussion with carers:
a	Supporting a relative to claim PIP, Employment Support Allowance and now Universal Credit is a highly difficult and stressful process – as can be attested by the Money Advice Unit, the Citizens Advice Bureaux and frequent reports in the media. Carers will see little point in going through this difficult process and helping a relative to claim higher or enhanced benefit rates if this is simply going to result in higher charges for social care.
b	<p>The County Council’s financial assessment process is also a difficult and daunting affair with little guidance for example on what is Disability Related Expenditure. Carers feel that it lacks transparency and feels quite obstructive. As one carer commented, <i>When my son moved into supported living I was quite unaware what Disability Related Expenditure would be generated and so I did not know what to include. It did not occur to me that he would run up costs washing bed linen daily for ‘sleep in staff’, have the heating on constantly as it was ‘a place of work’ or that he would have to pay staff travel costs. I needed some guidance from the Income Team but this was not provided.</i></p> <p>Another commented, <i>Within most BME communities families still take care of their elders, I have my mother-in-law living with us and my husband and I take care of her. But with us all living together at home, it is very difficult to show what is Disability Related Expenditure when we are shopping together, heating the house all day for her, doing the communal laundry.</i></p>
c	Many people in supported living who have large support packages in terms of 1:1 or 2:1 support often have no allocation for activities in their care plans and have to cover the costs from their benefits. Taking part in activities, such as swimming, trampolining, gym, horse riding, may be very important for adults with autism spectrum and learning disabilities to help manage anxiety and stress and to enable them to live safely and comfortably in supported living. They also face other costs, for example one adult

	<p>with autism and learning disability who needed 2:1 support paid £80 each month for his second support worker's bus pass.</p> <p><i>As one Dad said, My son can't use his benefits to pay charges and to fund his day-activities and other costs. If he does not keep active he may need more specialist input with medication as previously – his placement may even be jeopardised. This doesn't make sense.</i></p>
d	<p>Adults with physical disabilities often have to purchase continence products and pay for podiatry and extra physiotherapy in order to maintain their physical abilities. Care workers are not allowed to cut toe nails and two carers described their adult sons having nails that were particularly difficult to cut as the skin appeared to adhere to the nail. They were paying £45 for a podiatrist to cut them.</p> <p>Similarly the Hertfordshire Community NHS Trust which provides the Bladder and Bowel Service (Continence) is limited in the number of continence pads they can prescribe. This means most people using the service have to buy additional pads themselves.</p> <p>We understand that the County Council cannot meet any of these costs as they are categorised as health expenditure although the NHS does not fund or provide them on an on-going basis. They do, however, relate to the individual's disability and it would seem reasonable for them to be included in the financial assessment as Disability Related Expenditure.</p>
e	<p>Carers report anecdotally that they have seen a reduction in social care support; this is reflected in the State of Caring Survey 2016, where Carers UK reported that, <i>A third (34%) of respondents to our survey said that they or the person they care for has experienced a change in the amount of care and support services that they receive. More than half of those reporting a change (59%) said the amount of care and support they receive had been reduced because of cost or availability of services.</i></p>

	<p><i>This includes 12% who have cut down on the amount of care and support they get because the cost has increased or their personal budget no longer covers it, and 13% said that the care or support service was closed and no replacement was offered.</i></p> <p>The report of the 2016 survey also reported: <i>For those who are asked to make a financial contribution towards the cost of care and support, nearly half (47%) say they struggle to afford to pay for it.</i></p> <p>Carers who are parents of adults with physical or learning disabilities also tell us that they regularly subsidise their son or daughter’s care and, again this has been reflected in national research, <i>The cost of care continues to be a significant issue for families with the cost of paying for care services often falling on families even in situations where the state is responsible for meeting care costs. Increasingly, care and support is provided through Direct Payments – cash payments given to people with care needs in place of local authority arranged community care services they have been assessed as needing. Direct Payments are intended to give users greater choice in their care.</i></p> <p><i>Responses to our survey suggested that for many Direct Payments are not covering the cost of care. A quarter (24%) of those caring for someone with a Direct Payment are supplementing the payment as it does not cover the cost of care. (State of Caring Survey 2014, Carers UK.)</i></p> <p>We are concerned that increases in charges for social care will result in more people reducing the services that they use which will impact on family carers and also on the sustainability of the home situation.</p>
5	<p>In terms of the impact of increased charges on carers – as noted above, many carers, particularly parents, are already subsidising the costs of meeting a relative’s support and social care needs but this is not sustainable. The financial impact of caring has been well researched and documented with Carers UK reporting in 2016 that <i>Those responding to the survey are managing on low incomes with over half (51%) of them</i></p>

managing on a gross household monthly income of less than £1,500.

44% are struggling to make ends meet rising to nearly half (48%) of those caring for 35 hours or more per week. A quarter of carers (26%) report that they have been, or are currently, in debt as a result of their caring role.

More worryingly the report notes Financial hardship is putting further pressure on carers' ability to get practical and emotional support with their caring role as 13% of those struggling financially are cutting back on practical support with caring and nearly two thirds (64%) are cutting back on seeing friends and families, increasing the isolation that many carers experience.

Increasing charges will inevitably put more pressure on family carers' budgets and may drive some to cut back further on the social care services available. In some cases this will lead to carer breakdown and higher care costs for the statutory services. 38% of carers who responded to our Hertfordshire State of Caring Survey 2015 said that they had reached breaking point. Of these some 30% either gave up work or reduced their working hours and in 16% of cases their relative either went into hospital or residential care.

Family carers have told us that they feel disregarded and that their contribution to their relatives' care and well-being is under valued compared with the pressure to charge for social care. They cannot believe that the community would consider it right for some 8,000 disabled people to have to pay charges to bring in an extra £3 - £4million when that amount would be readily raised by a very small increase in Council Tax. They recognise the pressure on local government budgets but are also aware of the extra money recently released by central government for social care. They feel that they and their families are being squeezed between these two arms of government and their voices are not being heard.

However as a positive contribution, carers suggest that bringing Domiciliary Home Care services back in-house and using modern technology to manage the system would result

	<p>in improved services and reduced costs. They also believe that investment in employment support for many people with disabilities would encourage many who wish to work to take up paid employment and so reduce pressure on social care.</p>
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