

Carers in Hertfordshire

Response to Hertfordshire Adult Care Services' consultation on overnight respite care/ short breaks services for adults with a learning disability – *speaking up for family carers.*



1	Introductions
1.1	A carer is a person who provides unpaid care and support to a relative or friend who could not manage without their help. This includes parents or siblings caring for an adult with a learning disability
1.2	<p>Carers in Hertfordshire (CinH) is a countywide charity, which was set up by carers in 1995. The organisation's aims include:</p> <ul style="list-style-type: none"> ➤ Enabling carers to participate in service planning and decisions ➤ Providing a platform for the voice of carers ➤ Ensuring carers have an opportunity for a life outside caring <p>While we are aware that many individual carers have responded to this consultation basing their comments on their own experiences, it is part of our remit to respond on behalf of the wider carer community with reference to the themes and priorities that have come forward.</p>
1.3	Over 30,000 adult carers are currently registered with CinH, 2,000 of these identify as carers of adults with a learning disability and a further 5,700 identify as parent carers of a disabled child or young person.
1.4	<p>It is our experience that carers of adults with a learning disability are less likely than other carers to register with organisations such as Carers in Hertfordshire and to engage with the services we offer. This is, possibly, because they have adjusted to their long-term caring role over time with the support of services provided by health and social care and so they are no longer feel the need to seek information, peer support or advice.</p> <p>Carers of adults with a learning disability do however engage and speak up when service changes are proposed, which they fear may have a negative effect on the quality of their relative's life and/or on the stability of their family situation.</p>
2	The importance of having a break from caring
2.1	The NHS Commitment to Carers 2014 acknowledges that: <i>Caring responsibilities can have an adverse impact on the physical and mental health, education and employment potential of those who care, which can result in significantly poorer health and quality of life outcomes. These in turn can affect a carer's effectiveness and lead to the admission of the cared for person to hospital or residential care.</i>

	<p>This acknowledgement of the adverse impacts of caring on carers; health and well-being is re-asserted in the NHS Long Term Plan 2019 which states: <i>Carers are twice as likely to suffer from poor health compared to the general population, primarily due to a lack of information and support, finance concerns, stress and social isolation.</i></p>
2.2	<p>We know that the right support can make a positive difference to carers' well-being and to the sustainability of their caring role. The Carers UK 2017 national <i>State of Caring Survey</i> asked what would make the most difference to improving carers' health and well-being and reported that <i>Regular breaks from caring was the most popular choice, with 2 in 5 (42%) placing access to breaks in their top three things. This was followed by good quality care services for the person they care for (35%) and a better income (32%).</i></p> <p>The benefit of the right support is reinforced in the Carers UK 2019 <i>Carers at Breaking Point</i> survey which reports that: <i>Carers talk about how their lives can be transformed by good care services – which give them the confidence to take time for themselves, go to work or just to rest without the constant worry of what is happening to the person they care for.</i></p>
2.2i	<p>The positive impact of having a break was also reflected in carers' responses to Carers in Hertfordshire's own <i>State of Caring in Hertfordshire Survey 2018</i>, where 61% of respondents said that better access to breaks and /or being able to take part in leisure activities would improve their well-being.</p>
2.2ii	<p>The Carers UK 2019 report <i>Carers at Breaking Point</i> also highlighted the difficulty that many carers experience in securing sufficient breaks. This very recent research report found that 46% of carers had not been able to take a break even though they wanted to; 39% had been able to take a break but would have liked more and only 8% of carers had been able to take sufficient breaks. Confirming findings about the positive impact of taking a break the report also found that of those carers who had been able to take a break, <i>Almost 7 in 10 (69%) said that the break had a positive impact with their health and well-being improving as a result.</i></p>
2.3	<p>We believe that whilst an overnight respite break benefits the family carer – it is also an important experience for the person with learning disabilities. It gives them a break from the family home, the opportunity to socialise with peers and develop their independence and it is also good preparation for possible future placements in supported living or residential care accommodation. We would therefore expect overnight respite services to be considered at their annual needs assessment or review.</p>
2.4	<p>Additionally, the Care Act 2014 gives all adults caring for another adult(s) the right to an assessment from their local social services authority. These assessments look at the impact of the carers' caring role on all aspects of their life and what support they and their families need as a result. It would be helpful to know how many Hertfordshire</p>

	carers of adults with a learning disability have had a carers' assessment in the past year when they have been able to discuss their need for an overnight break. Anecdotally, we can report that when we have asked carers whether they have had a recent carers' assessment, very few recall having one.
2.4i	A further significant national finding is that only one quarter (26%) of the carers who responded to the Carers UK 2019 Carers at Breaking Point research, said their need to have regular breaks from caring was sufficiently considered in their carer's assessment.
3 Consultation process	
3.1	Earlier this year CinH became aware that proposals were being considered to reduce the number of overnight respite services/beds commissioned or provided directly by the County Council as block contracts. ACS senior officers advised that a consultant had been commissioned to review the use of beds in eight units and that a desktop exercise had been undertaken which had shown significant under occupation across the service. We were also advised that families of younger adults prefer to use Direct Payments to buy other forms of respite. There appeared to be an initial conclusion that fewer beds were required and, given the background of significant pressure on budgets, it would be appropriate to reduce the number currently being funded and secure budget savings in the region of £900,000.
3.2	We sought assurances that adults with learning disabilities and their families would be consulted about any such proposals and a series of consultation events have been held across the county from 11 September to 1 November 2019.
3.3	Members of the CinH Involvement team have attended nine of the ten public consultation meetings held during this period. The attendance of family carers at these meeting has been patchy; indeed none attended the meetings held in Welwyn Garden City on 16 September and in Letchworth on 19 September. As the consultation does not propose closing the respite centres which serve those areas (St Michael's House and Meadow Wood in Welwyn Garden City and Scarborough House in Stevenage) it may be that local families did not consider that their service will be affected and so saw little purpose in attending. This is a concern as a reduced number of beds, even against levels of under-occupancy, will inevitably impact on flexibility in terms of families being able to book an overnight break and individual allocations of days/nights. However the families concerned may not have realised this. We do not know what consultation has been undertaken with people with learning disabilities who use these services or who may wish to use them in the future.
3.4	The County Council officers who led these meetings will no doubt report back on the issues raised but we have referred to many of the carers'

	comments and questions in paragraph 4 below.
3.5	We would also note that during the consultation period, it became apparent that only those families who are currently using one of the respite centres under review were initially invited to these meetings. Other families who might wish to make use of such a service now or in the future (including those currently known to the 0 – 25 service) were not invited to give their views. Accordingly we sent out a short questionnaire via our database and received replies from 77 carers. Their replies together with representations made by families at the consultation meetings and the case work that CinH carer support workers and carer advocate undertake have informed our response.
4	Issues identified
4.1	Access to overnight respite care/short breaks – the information provided to carers shows occupancy rates at the eight centres ranging from 46% to 86% in 2018/19 and 44% to 81% in the year to-date. This suggests significant under usage with plenty of capacity for families to access the service, however the desktop exercise and consequent proposals did not appear to take account of a number of issues that have become apparent – see below.
4.2	<p>Waiting Lists: A carer who attended the first public consultation event at the Jarman Centre told the meeting that her relative was on the ‘waiting list’ for overnight respite at Tewin Road but she had not been given any indication when the service would be available. At the second meeting at the Jarman Centre, another carer reported that her family were in the same situation and had been waiting some years for an overnight service. Three more carers who responded to our survey said that they were also waiting for an overnight respite service.</p> <p>Another carer referred to having to wait to move between respite services: <i>Our daughter has only just received respite at Hixberry Lane. She has attended other sites previously, Tewin Road and St Michaels and we waited 3 or 4 years before her name rose up the waiting list and we were offered 36 nights per year at Hixberry</i></p> <p>At the meeting held at Kings Langley, the officer presenting told the carers that there are no waiting lists and it seems that these - and possibly other - applications were never put forward or actioned. Something evidently had gone wrong.</p>
4.3	<p>Availability: 11 of the carers who responded to our survey said that they had requested overnight respite breaks but their request had been turned down and a further nine said that they had been told that there was nothing available in their area.</p> <p>Carer A: <i>I have been desperately asking for this since October 2018. My daughter had been attending the Pines and that stopped on her eighteenth birthday with no notice. No further respite has been arranged</i></p>

	<p><i>since she turned 18. I have asked the social workers allocated about this at every meeting but nothing has been offered.</i></p> <p><i>Carer B: We have been asking for overnight respite for three years but have been told it's not available in our area as places are full. It's disgusting that these services may be closed when we need them and are not told they are available.</i></p> <p><i>Carer C: Overnight respite is a very much needed service. I was told there were no places and there is no chance my son would get one.</i></p> <p><i>Other carers who are in touch with our advocate and with our carer support workers report being told that there is either a waiting list or no service –</i></p> <p><i>Carer D: Social care has just confirmed my daughter's care plan post 18, today. Again they have said her two night monthly respite in Hemel will take a while, "There is a three month waiting list....not sure why but that's what we're being told." I mentioned the consultation, the social worker knew. I pointed out that her message is not consistent with the public message that beds are underused...she just waffled a lot and said she didn't know and kept repeating same thing. Over and over she went. Is a three month wait for respite (Hemel) typical?</i></p> <p><i>Carer D: I really needed some nights off from caring when my daughter turned 18 years and I asked the social worker if we could have an overnight respite service. We were told that there wasn't anything available and it wasn't until our advocate took my request up that we were told about the local centre.</i></p> <p><i>Carer E: Respite is something that I needed when my daughter was younger and had health needs less controlled than they are now. I made enquiries then and didn't get very far with social services with it.</i></p> <p><i>Some other carers told us that problems with the system led to a service breakdown – Respite was agreed for Tewin but broke down due to the incompetence of the worker and Social worker did not help when requested to rebook and then the person did not want to stay because it took so long.</i></p>
4.4	<p>Current service capacity: A family carer whose daughter has significant physical disabilities tried to arrange for her to attend St Michael's House for overnight respite at the same time as her close friend as this would be a good opportunity for them to spend time together and the break would be a more positive experience. However this request could not apparently be accommodated, which seems inconsistent with an occupancy level of 46% in 2018/19.</p> <p>The issue of capacity at St Michael's House was also raised by another carer who had contacted that centre enquiring about overnight respite.</p>

	<p>She said the manager there told her they only use four of the 12 beds because of staffing constraints.</p> <p>Capacity issues at other units have also been raised: Carer A: <i>I had to give back half of the allocated respite nights as I can't get a bed at Tanners Wood as no beds are available because they are full. I tried to use Tewin Road but getting there was hard as the transport has now been stopped.</i></p> <p>Similarly, Carer B: <i>Tanners Wood told me that they have no room. Transport has been stopped so we cannot get to Tewin Road anymore.</i></p> <p>Carer C: <i>We recently asked to increase the number of nights and were told that Tewin Road did not have capacity.</i></p> <p>In view of the proposal to close Tewin Road, one family who are currently using that service for overnight respite contacted Tanners Wood to ask whether their son would be able to access a service with them – the family reported as follows:</p> <p><i>We visited Tanners Wood this afternoon, the consultation document states that there are eight beds, that's not correct, there's seven. Tanners Wood advised us that they are at capacity with their Personal Emergency Evacuation Plan (PEEPS) for Service users in wheelchairs (which is a max of 4), so there is no space for our son. If Tanners Wood had capacity, which they don't, our allocation would fall from 40 days/ nights per year to just 24. At Tewin Road we can book 12 months in advance, at Tanners Wood we can only book 12 days in advance for the following 6 months</i></p>
4.5	<p>Information: Several carers who responded to our survey were unaware that overnight respite care was available or told us that they had had to pursue it for themselves:</p> <p>Carer A: <i>I have never been offered any overnight stays for my daughter – she is now 20 and I am not aware of this service. More information would be appreciated.</i></p> <p>Carer B: <i>I did not know about this sort of service.</i></p> <p>Carer C: <i>I was not aware of this service. Only once was 20 years ago when my son was going through crises he stayed for one night somewhere in Hemel – can't remember the name. Quite a distance considering we are in East Herts. Have never been offered it since and was not aware there were so many services, also surprised there is one in Hoddesdon. Obviously not a facility the council wishes people to know about!</i></p> <p>Carer D: <i>No knowledge and never been offered this service.</i></p>

	<p>Carer E: <i>I didn't know it existed!</i></p> <p>Carer F: <i>I have never used this service but we would be interested.</i></p> <p>Carer G: <i>I have two in my care, my spouse who has advanced Early Onset Alzheimer's' and my daughter who has Down's Syndrome. We have never been offered overnight respite for my daughter.</i></p> <p>Carer H: <i>We have never been offered any respite at all.</i></p> <p>Carer I: <i>No knowledge and never been offered this service.</i></p> <p>Carer J: <i>We were never offered respite care – I was struggling and the Carer Champion at my GP surgery told me about it and suggested that I contact social services.</i></p> <p>Carer K: <i>When we transitioned to adult services we had to research respite services and make the necessary arrangements. Social workers do not actively promote the services and therefore they are under-used.</i></p> <p>Carer L: <i>I did not know that there was funding available for this sort of service.</i></p> <p>Another carer has told us that a 0-25 worker suggested that she find her own respite care and then come back to the team so see if it could be funded.</p>
<p>5</p>	<p>Suitability of service: A number of carers have responded to say that they do want overnight breaks but they are not confident that the services available would be able to meet their relative's needs:</p> <p>Carer A: <i>The respite offered was unsuitable for my daughter's needs. We were offered Scarborough House and told we couldn't have anything else. It was Scarborough or nothing.</i></p> <p>Carer B: <i>We have not used respite homes (Scarborough is the nearest) as his needs could not be met – they thought that two tea visits would be enough to settle him in.</i></p> <p>Carer C: <i>Isabel Court and many of the other centres are completely unsuitable for my son. He has very severe autism and learning difficulties – they are completely under-staffed and cannot take disabled people who are challenging. We tried Isabel Court but it was not suitable for my son who is very severe and they could not look after him. There were only two staff for all the clients and my son needs 1:1 – this is also true for many of the others. Apton Road only has on staff for all the clients. The service is not fit for purpose – to help families who need it they need more staff and better facilities in some cases. There is a huge need for overnight respite.</i></p> <p>Carer D: <i>My son has autism, epilepsy, learning disabilities, is non-verbal</i></p>

	<p><i>and occasionally displays challenging behaviour. As a young child he would often try to get out of the house when bored or if he woke during the night, so that we never trusted that he would be safe in a respite service.</i></p> <p><i>Carer E: My daughter has complex needs including Type One diabetes but is only moderately learning disabled but the only respite place offered did not do blood tests, injections or carbohydrate counting. So she would not have survived.</i></p> <p><i>Carer F: Overnight respite needs to be adequately staffed so it is a positive experience and not just a baby sitting service.</i></p> <p><i>Carer G: We would definitely like to investigate if any other respite places were more suitable for our daughter who has a severe and complex disability.</i></p> <p><i>Carer H: My son is now 20 and although I would like to have overnight respite for him, I am not convinced that he would like to be away from home and with people who are not aware of his routines. I would also be very concerned for his safety and that of any staff and other youngsters around him if he became distressed.</i></p> <p>CinH is also in contact with two families who used to receive a respite care service from Nascot Lawn because of their relative's complex health care needs. They were not able to find a local Hertfordshire service for the person, once they turned 18 and have opted for expensive out of county placements. There will be other families in this situation as their children become young adults.</p> <p>The lack of an appropriate service for young adults with complex health care needs was echoed by the parent carer who spoke at the initial meeting of the Improving Healthcare Transition Collaborative held on 6 November 2019. This carer is a widower caring for a very medically complex son, now aged 17 years – he has been told that there is currently no overnight respite service available for this young man as he is too medically complex. This carer has given up Direct Payments as he found managing that system too demanding – the family is in receipt of Continuing Health Care but the carer does not want to manage a Personal Healthcare budget as, again that would be too demanding for him as he is trying to maintain his own business as well as a heavy caring role.</p>
6	<p>Quality of service: Some family carers have commented that they did not feel that there were sufficient age appropriate activities provided at the respite centre – particularly for younger adults – and so opted not to use them. This seems to be a particular issue for parent carers of young people moving from children's to adult services.</p>
6.1	<p>One father told he found his daughter (a very disabled young woman)</p>

	<p>sat in front of the television watching CBeeBies when her normal choice of TV programme would be series like EastEnders. That family no longer use an overnight respite service.</p> <p>Another carer explained that she stopped using the respite centre because of poor experiences there: <i>My son did go to Tewin Road but we took him out after six months as he was not happy and he stopped eating there. We never had a problem at Woolmer Drive (Disabled Children's respite centre), he is visually impaired + cerebral palsy, it seemed more suitable for the more able. He used to be in the dining room on his own as he can't see the television. I was told that he could take in his own things to play with and was then told by a worker that it was too noisy. I would never send anything in that was too loud + wouldn't have thought they could hear as he was on his own. Another time I picked him up early he was upstairs on his own, he is epileptic, the others were having breakfast downstairs.</i></p> <p>And another commented: <i>Due to low staffing, my son and others were unable to be taken to social activities with the local MENCAP group. Also the last time he was there, he was the only resident who was mobile and under 50 so he spent most of his time in his room.</i></p> <p>These carers were clear that they would like, indeed need, to access an overnight respite service where there were a range of activities available, sufficient staffing and a 'young vibe' for the younger adult age group.</p>
6.2	<p>However it should be noted that many families who are currently using the overnight respite care service do value and rely upon it so clearly expectations and experiences can be very different:</p> <p>Carer A: <i>My son has been at Hixberry Lane for five years or so. He loves it there so there is no problem getting him to go. The care workers there are awesome and he likes them all. It is reasonable close to where we live. He attends Earthworks twice a week and as it's so close there is no need for transport and one of the care workers just walks him there. My wife and I do not want any closures; we find the service is perfect for us.</i></p> <p>Carer B: <i>There is no way we could cope without respite care for our son.</i></p> <p>Carer C: <i>Our son has used Tewin Road for the past 25 years and is very happy there and with the staff who have brought him out socially and developed his confidence. Closure of Tewin Road would affect him badly – it is very difficult for people with learning disabilities to adjust to new circumstances.</i></p> <p>Carer D: <i>We regularly rely on this service for respite. Respite is for all of us not just the person who is being cared for.</i></p>

<p>7</p>	<p>Allocation of nights: Whilst we did not ask carers how many nights they are allocated annually this did come up in conversation and it is evident that there is a very wide range. Although it could be argued that each case is different and will need a different level of service, the range remains significant.</p> <p>One family, where a 65 year old gentleman is living with a sibling, receive an annual allocation of 28 nights – another family with a 66 year old gentleman living with a sibling receive an allocation of 11 nights. The second family would like an increased allocation but did not realise that they could ask for that.</p> <p>One family where the parents are in their early 60’s with a 35 year old son at home, receive an annual allocation of 60 nights, another family where the elderly mother in her early 80’s has her 50 year old son living at home receive an allocation of 32 nights. Again the second family did not realise that they could ask for an increase in the service.</p>
<p>8</p>	<p>Alternative overnight respite services: During the presentations at the consultation events, officers have referred to 50 other services that people are using in Hertfordshire which would be available to families on a spot purchase or direct payments basis. However officers have not been able to identify those services or to provide any details about them.</p> <p>A number of carers who responded to the CinH questionnaire did say that they were using an overnight respite service at Little Grove in Bushey. This is a not for profit community interest company which was set up in 2015 to work with children and young people who have a learning disability and provide them with support services, including overnight respite stays. It does not appear to cater for older adults.</p> <p>We also heard from carers who have been using overnight respite services at Nicole House, St Elizabeth’s Centre, Much Hadham. However carers understand that this service is due to close :</p> <p><i>St Elizabeth’s Centre, Nicole House is also closing at the end of December. It took us 18 months to get a place there. It is the only overnight respite place in the whole of Hertfordshire that deals with challenging behaviour and offers 1:1 care. We are devastated by this closure and I am worried we will not cope.....As I said, we spent 18 months fighting for it and now it’s closing, they said it was not financially viable unless it is full and it is not full because not enough people get referred.....The people who need this service most are not taking up places in centres like Isabel Court as those centres do not have the staffing to manage severe and challenging clients.</i></p> <p>When this closure was raised at the last consultation event, the officer said that he has heard that Nicole House is only closing for 18 months for refurbishment. However we have also been in touch with St</p>

	<p>Elizabeth's Centre and have been told that the current low occupancy rate has made it uneconomic to run. There was some discussion about this at the final event in Kings Langley where the following points were made:</p> <p><i>Social Workers are the entry point for the service and it doesn't seem that they always tell people about respite and related options, which could also be a reason St Elizabeth's is closing. Others carers present strongly agreed that they were not told about respite options or the details around Direct Payments, one lady said "Social Workers don't know about the respite homes, we had to do all the leg work ourselves" Another said that parents just don't know what's available.</i></p> <p>We also heard from carers who have made their own individual arrangements using Direct Payments to pay for a care worker to cover respite for them, either in their own homes or in the care workers' home. These arrangements are generally individual and not available for wider spot purchase: <i>I requested overnight respite when she was 17 and was told that there was no point getting her used to children's provision as we would then need to change when she was 18. I said that we couldn't wait until she was 18 and so agreed that we would get extra Direct Payments to pay our existing care worker to have her overnight at her house. We were allocated less than we asked for and so I have just asked for an increase to enable weekly overnight respite.</i></p> <p>Other carers have chosen an individual approach as they found this more personalised: <i>I found it better to find my own respite as we could go at my son's pace to settle in and it was more adaptable to mine and my son's needs.</i></p> <p>During the consultation officers have also made reference to the Shared Lives project as offering respite options. However a Shared Lives worker who attended one session acknowledged that they have very few Shared Lives providers offering respite relationships. The point was also made the Shared Lives providers operate from their own homes which are generally not adapted for people with access or significant mobility issues.</p>
<p>9</p>	<p>Direct Payments: Whilst Direct Payments can work very well for some families, it is also true that this places a heavy responsibility on to the family carer to project manage their relative's care package and also requires them to step up when – for example – a care worker/personal assistant is unwell. Carers tell us that this is not an unfamiliar experience. There can also be significant problems for family carers finding services to use the Direct Payments to buy – and this is an issue that came up during the Community Opportunity engagement events that have also taken place during the early autumn.</p> <p>While there is some evidence that some families prefer to use a Direct Payment the assumption that parents of younger people generally prefer</p>

	<p>Direct Payments to service provision has certainly been challenged by a number of family carers. At the Community Opportunities event on 21 November 2019, the following questions were put:</p> <ol style="list-style-type: none"> 1. When you assess someone for Direct Payments do you consider the costs carried by family carers who project manage their relative's package? 2. How do parents find out what services are available for their son or daughter? 3. We need a menu of services that we can look at and choose from – can HCC please provide that as we are losing sleep with worry trying to find a suitable alternative as a service has closed down? 4. How do we know that the quality of service provision is ensured? 5. What monitoring is undertaken to ensure that PAs are appropriately trained and supported and delivering a quality service? People are using Direct Payments for buying PA services – that is HCC funding – so surely HCC has a responsibility for monitoring them? 6. Is there any intention of HCC producing a list of approved PAs for people to refer to? 7. Surely HCC has the responsibility for monitoring all the services being purchased with Direct Payments irrespective of whether you contract directly with those services or not? 8. How much analysis is done about what people are using Direct Payments for? <p>And the following comments recorded;</p> <ol style="list-style-type: none"> 1. Some families have no choice but to accept Direct Payments as there is so little available. 2. Direct Payments suit HCC as they are easier for HCC to administer. 3. The Direct Payment hourly rates do not meet the costs of advertising, recruiting, training and paying a decent rate of pay to workers. 4. It is difficult to contact a social worker – you 'phone the duty team but no-one gets back to you. Some families need a named social worker but some don't. This can be really difficult when you are trying to resolve an issue about Direct Payments (change of service purchased) or when you face other problems. It would be helpful to have a named person to get back to in such circumstances. 5. HCC is responsible for market development in terms of social care – we need more well trained and appropriately qualified PAs in the county. We need a county-wide strategy to address the recruitment and retention of this workforce.
10	<p>Person-centred approach: Carers whose families are currently using Hixberry Lane, Isabel Court or Tewin Road have repeatedly questioned why these three services – which are among the top performers in terms of occupancy rates are selected for closure while centres which are less well used are to be retained. Officers have</p>

	<p>explained that other units have had considerable investment to modernise and improve the accessibility of the buildings whereas these three sets of buildings would require investment if they are to continue in use.</p> <p>Whilst this argument makes sense in terms of the needs of the service, carers argue that it is not consistent with person-centred practice.</p>
10.1	<p>Carers also note that the proposal to close three well used centres means that more families would experience disruption and worry and more service users would be faced with a major change than would otherwise be the case. Again carers argue that these proposals are therefore driven by the needs of the service and are not consistent with a person-centred approach.</p>
10.2	<p>Similarly the assumption within the proposals that 15 miles travel is reasonable – ignores the needs of families who may well not all have access to a private car and ignores the benefits to the individual with learning disability of accessing a service in their own community. These allow easier access to their regular day activities in familiar surroundings and also support the principle of having a presence in your own local community. (https://www.optionsforsupportedliving.org/blog/john-obriens-five-service-accomplishments)</p> <p>At some of the consultation events, carers have commented that accessing a transport service for respite was a hard fought battle. They asked for a firm commitment that transport would continue to be offered if they were forced to change respite service. This request was acknowledged but no commitment was given, it was said that a further assessment would have to be carried out.</p>
11	Conclusions
11.1	<p>While the desktop exercise revealed issues of under-occupancy there does not appear to have been any further work with families to reveal underlying causes beyond an assumption that the present level of service is no longer required. We consider that the issues of 'waiting lists', service availability and capacity, quality and suitability and the lack of information for families about overnight respite care and allocation levels are all worth investigating further. These may well reveal a continuing demand for such services, particularly to sustain family situations and the health and well-being of family carers but with some development necessary to improve and extend what is available.</p>
11.2	<p>We are also concerned that suggestions about a wide range of alternative overnight respite options and a carer preference for Direct Payments need further investigation.</p>
11.3	<p>In terms of co-production – this level of consultation is a halfway mark on the Ladder of Participation/Co-production ladder (see attached) which is disappointing given Adult Care Services commitment to working</p>

	<p>towards a fully co-productive approach. We would have hoped that carers and people using the service could have been involved at an earlier stage to discuss the reasons for under-occupancy, challenges and barriers to access the service and other options which are available or which might be developed. It would have been more inclusive to seek to inform and engage carers known to services, who do not currently use overnight respite. From our evidence some of them may choose to use it, if they are informed that it is an option and that there may be availability.</p> <p>We believe that this inclusive approach would have helped shape proposals for the future. We would hope that this can be a learning point for service development/review.</p>
11.4	<p>We understand that the outcome of the consultation will not be included on the agenda of the Adult Care Services Cabinet Panel on 2 December 2019 as previously advised and that consideration of final proposals will now be deferred to February 2020, pending a further period of consultation</p> <p>We would strongly recommend that proposals be put on hold to allow the full involvement of families and people using the service to co-design and co-produce an overnight respite care service that meets the needs of Hertfordshire families going forward – and, in particular, that provides a service for adults with challenging behaviour or complex health issues who do not appear to have access to adequate overnight respite at the present time. CinH would be able to support a full involvement exercise by reaching out to all carers known to our organisation and to partners including for example the Hertfordshire MENCAP groups and the private and voluntary day service providers, ensuring that family carers are provided with the necessary information, hosting workshops, canvassing examples of good practice from the UK's carer centre networks and supporting positive discussions between family carers, service commissioners and providers.</p>

<https://www.england.nhs.uk/publication/nhs-englands-commitment-to-carers/>

<https://www.longtermplan.nhs.uk/>

<https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017>

<https://www.carersuk.org/for-professionals/policy/policy-library/carers-at-breaking-point-report>