

Carers in Hertfordshire

Submission to the Health Scrutiny Committee

Wednesday 21 March 2018



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 caring for a disabled child - often described as 'parent carers' and young carers aged 18 years or younger who support an ill or disabled relative - usually a parent or sibling.
1.2	Carers in Hertfordshire (CinH) is a countywide Charity, which was set up by carers in 1995. The organisation's aims include: <ul style="list-style-type: none"> ➤ Enabling carers to participate in service planning and decision making ➤ Providing a platform for the voice of carers
1.3	25,718 adult carers are currently registered with CinH, 4,214 of these identify as parent carers. We are also in touch with 1,436 young carers, many of whom have a disabled brother or sister.
2	Question 1: Is the Proposal in the interests of health services in Hertfordshire?
2.1	When considering the possible consequences for local health services it is important to recognise the negative impact of caring on the health and well-being of parent carers –
2.1i	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>
2.1ii	The Carers UK 2017 national <i>State of Caring Survey</i> (p.7) found that: <i>People looking after a disabled childwere more likely to report stress and anxiety as a result of caring than other groups. They were also more likely to say that caring had impacted upon them having a balanced diet and their ability to do exercise. People caring for a disabled child were the most likely group to report having suffered from depression because of their caring role (54%).</i>

2.1iii	The CinH 2018 <i>State of Caring Survey Hertfordshire</i> has just closed but early findings report that <i>66% of parent carers of children with higher or complex needs said they had neglected their own health; 49% had missed or not made a health appointment for their own needs and 85% said that they felt isolated.</i>
2.1iv	In terms of general well-being, we know that caring can have a negative impact on family relationships: <i>Research (Contact a Family 2004, No Time for Us) shows that parents with disabled children are more likely to experience a relationship breakdown than parents of non-disabled children.</i>
2.1v	It is also important to recognise the impact of having a disabled brother or sister: <i>Siblings of children with disabilities are at a greater risk than average of developing emotional issues, anxiety, and stress....they may face peer problems, as well as a lack of engagement in extracurricular activities and academic issues as a result of limited time and money.</i> (Psychology Today, <i>What About Me?</i> June 2014).
2.2	We know that the right support can make a positive difference for families with a disabled child and mitigate the impact of caring on their health and well-being –
2.2i	Parent carers responding to the 2018 CinH Survey said that <i>Access to Short Breaks</i> would make the most difference to their health and wellbeing. This is reflected in the Carers UK 2017 Survey which reported: <i>Respondents were asked what would make the most difference to improving their health and wellbeing. Regular breaks from caring was the most popular choice, with 42% placing access to breaks in their top three things.</i>
2.2ii	<i>Research shows short breaks are one of the most effective ways of improving the quality of life for disabled children and their families (Parliamentary Hearings on Services for Disabled Children 2006).</i>
2.2iii	It is accepted that having a regular break enables parent carers to carry on caring safely and well and to spend valuable time with other children in the family. However they need to be confident that the staff providing the break have the right knowledge, skills and attributes to understand and respond appropriately to the needs of the child or young person they care for. Carers will not otherwise use the service.
2.3	Nascot Lawn has provided an NHS funded nurse-led overnight and day-care service for children with complex health needs for many years (see the CinH submission to the Nascot Lawn Respite Centre Funding Topic Group, 6/09/2017 for the history of the service). The building is well equipped to meet the needs of children with significant physical disabilities and has the space to accommodate wheelchairs, specialist beds and hoists.

	<p>We are concerned that unless an equivalent service can be provided to those families currently using Nascot Lawn and to those other families awaiting a referral to that service, the health and well-being of the parents, siblings and of the disabled children themselves will be adversely affected. This will inevitably have an impact on the wider health and social care system in Hertfordshire both in the short and longer term. In respect of young carers/siblings in particular, we are concerned that the opportunities to '<i>Thrive</i>' and to '<i>Take Part</i>' would be significantly compromised by any reduction in the breaks provided.</p> <p>We are aware that the current group of families who have received a service from Nascot Lawn have had their allocations reduced and that there are continuing issues about capacity, space and staff training at some other services.</p>
3	<p>Question 2: Are there any alternative service proposals available to Herts Valleys Clinical Commissioning Group HVCCG and the County Council that would address the current and future needs of CYP with complex health and social care needs requiring respite care in Hertfordshire?</p>
3.1	<p>It is evident that the County Council and HVCCG had been in discussions about the future of overnight short breaks services prior to HVCCG's decision to cease funding Nascot Lawn. The briefing paper provided by the Director of Children's Services to HCC about the Nascot Lawn petition (18 July 2017) referred to a review of overnight short breaks services, carried out in 2015, which reported a reduced demand for overnight short breaks to meet social care needs but no reduction in the number of children with complex medical needs who would need to access such a service. That briefing also stated:</p> <p><i>On 22 September 2016 a report was prepared by Herts Valleys CCG (HVCCG) and the County Council which was taken through the respective programme/management boards. The paper made the following recommendation: To jointly commission a fully integrated Overnight Short Breaks service model for health and social care. The recommendation was agreed by both programme boards.</i></p> <p>Work to progress this decision was presumably put on hold when HVCCG made the decision to cease funding Nascot Lawn in December 2016/January 2017 (HVCCG Background Paper for the Nascot Lawn Topic Group, 6/09/218) although there is some disagreement between HVCCG and HCC about when that decision was communicated to County officers. We are however aware that discussions have since continued and in a letter to parents dated 7 March 2018 Mrs Kathryn Magson of HVCCG noted</p>

	<p><i>‘we had a constructive and helpful meeting with officers at the council. We have discussed and agreed to work up a Hertfordshire-wide joint commissioning approach to overnight short breaks, led by the council, with the facilities they currently commission.’</i></p> <p>It appears that the intention is to reduce the number of overnight short breaks services in Hertfordshire to three, i.e. based on the facilities that HCC currently commissions. We note the findings of the 2015 review mentioned above but our experience is that parent carers currently struggle to access overnight short breaks. Findings from the very recent CinH 2018 <i>Hertfordshire State of Caring Survey</i> report show that:</p> <ul style="list-style-type: none"> • 36% of parent carers had not had a day off in 5 years • 47% of parent carers had not had a weekend off in 5 years • 74% of parent carers had not had a week off in 5 years <p>We are also aware of a survey that was undertaken by Herts Parent Carer Involvement with families in 2016 focussing on overnight short breaks where a third of the respondents were not satisfied with the number of ‘overnights’ allocated to their child.</p> <p>We are therefore not confident that a reduction to three units will provide sufficient capacity to meet the needs of families in Hertfordshire. We are also concerned that the locations of the HCC commissioned services – The Pines in Hertford, Peartree in Welwyn Garden City and West Hyde in Rickmansworth – will require lengthy journeys for some children and families accessing, for example, after-school tea visits, mid-week stays or day-care. When we asked families in 2009 what they considered a reasonable travel time to and from a respite care unit, the overwhelming preference was for a 20 minute journey each way. This was predicated on a having five respite units in the county, the closure of Wilbury House in 2013 clearly impacted on journey times for families in North Herts and this proposed further reduction will mean that journey times may be difficult for many families.</p> <p>We recognise that short breaks include a range of provision including sitting services, buddying or befriending services, clubs, play schemes, shared care as well as overnight respite. We also recognise that some families do not need or want overnight breaks for their children and find the other services sufficient to meet their family’s needs. However the aim of the Aiming High for Disabled Children programme in 2008/09, which led to a re-organisation of overnight short breaks services was to improve short break provision specifically for:</p> <ol style="list-style-type: none"> a) Children and young people with complex health needs, and b) Children and young people with learning disability (with or without autism) and challenging behaviour
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	<p>And it is these children and their families who we believe, continue to need overnight respite. We support a further review of the current and predicted number of children/young people in these two categories with input from the Special Schools and from the Positive behaviour, Autism, Learning disability and Mental health Service (PALMS) to ensure that there is sufficient provision within county to meet the need.</p>
	<p>Question 3: How will the integration and joint responsibilities between HVCCG and the County Council be arranged and managed going forward?</p>
3.1	<p>This is primarily a matter for HVCCG and HCC. However current commitments to Co-production suggest that those families who are either currently using the services which are to be delivered via an integrated system or who are likely to be referred to them, should have the opportunity to be directly involved in the design, development and delivery processes.</p>
4	<p>Conclusion</p>
	<p>Carers in Hertfordshire is keen to work with the County Council and the two Clinical Commissioning Groups to develop a high quality overnight short breaks Hertfordshire offer for the two groups of children and families mentioned above. We are appending a check list of what parents have told us they would want and expect from such a service which we trust will be helpful.</p>