

## Health Scrutiny Committee – 21 March 2018 - Parents' Evidence

### Introduction

Evidence has been drawn from the experience of many families who have provided their input throughout the campaign to save Nascot Lawn. However in this report we have particularly focused on the families whose children have very high health needs - some receiving Children's Continuing Healthcare (CHC), others not - because we believe these children should set the standard by which medically supported respite can be judged. If we cannot deliver respite for these children and their families in Hertfordshire, then we cannot say we live in a County of Opportunity.

### Questions

#### 1 Is the Proposal in the interests of health services in Hertfordshire?

No. It would leave the County without a facility for overnight respite for its most medically complex children. This is evidenced by the experience of one family (in receipt of Continuing Healthcare (CHC)) who since the threatened closure of Nascot Lawn have had Richard's House Hospice and Haven House Hospice (which has limited capacity and so no room to increase care packages if a child's situation deteriorates) suggested to them as suitable alternatives, they are outside the county boundaries of Hertfordshire. Another suggestion, Aurora Meldreth Manor is a children's home and is situated in Royston, a long way from families based in Watford. It currently has no capacity to admit additional children for respite. Herts Valleys Clinical Commissioning Group (HVCCG's) first evidence paper to the Health Scrutiny Committee Topic Group of 8 September 2017 suggested that Keech Hospice in Bedfordshire could provide respite care to Herts Valleys children in receipt of CHC. HVCCG have now acknowledged in correspondence with parents that this is not a possible respite care location. Also, during the Judicial Review, The Hon Mr Justice Mostyn commented that HVCCG's suggestion that respite should take place in a hospice setting was "inappropriate".

Another child (not in receipt of CHC) has been placed out of county for respite. Their experience of booking nights is that it is the policy of the provider to book nights for all the families from the other county first and then to consider the requests made by their family - they are last in line because they are from Hertfordshire.

**Please do not allow this proposal to go unchallenged, families whose children have high health needs will not have a suitable respite centre within the County to meet their needs. It is unacceptable that those with the highest needs should have the furthest to travel and should be last in the queue when it comes to family support.**

#### 2 Are there any alternative service proposals available to 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?

We are aware that since the families' Judicial Review, Hertfordshire County Council, Herts Valleys CCG and East and North Herts Clinical Commissioning Group (ENHCCG) have acknowledged their joint responsibilities for providing respite support to our children and are working together to produce a proposal to meet our needs. It is appalling that it has taken legal action to force this interaction to take place and gives us very little confidence that all parties truly have the interests of our children and families at heart. We would like you to judge any alternative joint service proposal against the following principles:

### **The need for a Registered Nurse**

Many of the children who use Nascot Lawn currently benefit from the presence of a Registered Nurse leading the planning and delivery of their care - but **some children cannot be safely left in respite care without a Registered Nurse present**. We would like the Health Scrutiny Committee to note that the national criteria for Children's Continuing Healthcare is not a sufficient measure by which a decision could be made about whether a child required the presence of a Registered Nurse. So when Health Scrutiny Committee members consider the numbers of children who require respite overseen by the Registered Nurse they should not rely solely on the numbers of children who currently qualify for CHC. In East and North Herts CCG, a 'sister' service to the CHC team recognises and provides nursing support in respite to a wider group of children who do not qualify for CHC but still have a very high level of medical need and a number of procedures requiring a Registered Nurse, because it is recognised that this service keeps children out of emergency hospital care.

The accounts of the medical care which must be delivered by a Registered Nurse which follow belong to children who do and do not qualify for CHC:

#### What care does a Registered Nurse provide for your child?

##### Child 1 meets CHC criteria:

Seizure management & recovery, gastrostomy and jejunum feeding, specialist feed management, port-a-Cath management, recent Nissen fundoplication re-do, medication administration (regular, PRN, rescue), oxygen delivery (routine and emergency), suction (oral and nasal pharyngeal), universal precautions due to MRSA colonisation, chest physiotherapy, oxygen saturation and heart rate monitoring, nebulisers (asthmatic and antibiotic), AirVo 2 (optiflow) specialist oxygen delivery equipment, pain management.

##### Child 2 does not meet CHC criteria:

Seizure management and emergency medication administered (midazolam). Be able to assess and administer extra morphine for breakthrough pain in addition to slow release morphine. To be aware of risks and treatment of Haemophilia. I have been informed by school that MST slow release morphine and liquid morphine can only be given if two trained nurses are present.

##### Child 3 meets CHC criteria:

Seizure management (recovery), oxygen (seizures), saturation & heart rate monitoring (seizures), medication administration (regular, PRN, rescue), occasional need for NG tube due to seizures.

##### Child 4 meets CHC criteria:

Emergency care of Hickman Line including what to do in event of break in line, protocol to follow if eloped a temperature, recognising signs of sepsis. Trouble shooting problems on Bodyguard pump that infuses TPN. Preparing JPEG feeds and administering. Giving of medication via JPEG. Introducing a catheter into JPEG site if the tube fell out to keep stoma open until he can get to hospital and have it put back in under General Anaesthetic. Cleaning and redressing the Hickman Line site. At no time would a person who is not a qualified nurse be allowed to access Hickman line. This protocol is set out by the hospital we are under.



*One month's medication for a child who does not meet CHC criteria. In a respite setting, all medication which needs administering would have to be overseen by a Registered Nurse:*

### **The importance of 'local'**

As noted above, the alternative respite solutions currently proposed to the families of children who have high medical need are either out of County, or are a children's home at the northeast apex of the County (this is not a respite setting and is full). The current suggestion of putting additional medical equipment into The Pines, Peartree or West Hyde has not yet materialised and there are reports going back to 2011 highlighting the inadequacy of West Hyde for wheelchair users of larger postural support chairs. When one family asked about the specialist cot bed their child would require being put into an alternative setting (The Pines) in order to make it suitable, the child's parent was told, "the cot required would block the room and render it unusable by anyone else". It does not seem likely that without significant building work to increase capacity and make the physical space suitable for high needs children, Hertfordshire currently has a respite care centre that is physically able to take the most disabled children and meet their respite needs.

The desire for a respite centre to be local to families who currently use Nascot Lawn is not just a preference, it is vital to the safety of their children. Children with high medical needs, even with the best care, do often need to travel to hospital as an emergency. In this case, having their families close by and therefore able to meet the ambulance as it arrives at A&E, being able to call up a child's medical notes quickly and communicate complex information crucial to their care is very important to the safety of the child. One of the Nascot families says that 7 volumes of their child's medical notes are at Watford General - vital information which could not be quickly transferred. Doctors in acute services rely on parental expertise to help guide their treatment when a child has complex needs. The location of any future nurse led respite centre should also be within close transfer distance to the child's usual hospital.

The families whose children have high medical needs all highlight how unhappy they would be about the distances they would have to travel and ask their children to endure (many of these children cannot regularly use school transport services because their medical needs are too great for a long journey 'on the bus') unless an alternative respite centre were close to home.

**It is vital that any future high medical needs respite should be 'local' for an easy transfer to the child's usual hospital. As yet, there is no alternative overnight respite setting suitable and available to high medical need children within Hertfordshire County Council's overnight respite offer.**

#### **Centres under pressure**

We ask the Health Scrutiny Committee to consider the pressure placed on the three remaining overnight respite centres if Nascot Lawn closes. In addition a children's home has been suggested as a suitable respite location for some children, one parent was invited to visit it, "When I got there it became apparent, very quickly that there was no way my child could go as it is undergoing major changes and building works. I asked when they thought there would be capacity and the staff member couldn't tell me. I asked for rough ball park figure, for example weeks, months or years and was told maybe 2 to 3 years." We also know that West Hyde is struggling to recruit staff to meet the current allocated hours of its users.

Given that our children will all require complex care plans, transitional arrangements and are likely to have a high hours allocation, are Health Scrutiny members confident that Hertfordshire County Council would be able to provide an equivalent level of respite care to all of the eligible children (Nascot Lawn users and other existing overnight respite users)? This is particularly pertinent because high medical needs children cannot be integrated in the same setting as behaviourally challenging children so wholly separate timetables will need to be drawn up.

This means that the families' choice of nights will be limited to the 'medical needs nights' of any given centre and it is also likely to affect a family's ability to book a number of nights in one block, allowing them to take siblings on short holidays or get essential building work done without exposing a child with high medical needs to potentially harmful dust and painting work. As one family said, "My family do not live close by and my father is not in good health. It is extremely difficult to take my child away because of the equipment he needs so if I didn't have this care I would feel isolated from my family."

**We ask Scrutiny members to ensure any alternative proposals would guarantee families the ability to have short block bookings of time and ensure it will be possible to allow families some flexibility in the days of the week they book respite for.**

#### **Daycare**

Currently Nascot Lawn provides a day care service for children from birth to 5 years old (or whenever they transition to school). Alternative service proposals must consider a service commitment to these children as all other County Council respite settings currently are restricted by Ofsted requirements that the children should be aged over 5 years. We are not proposing an overnight service should be available for children aged under-5 but a respite service involving a Registered Nurse where appropriate should be developed in an appropriate setting for children aged 0 - 5 years. **Councillors should ensure any plans relating to this service have clear delivery timescales as currently, in Herts Valleys area of the County, no such services exist, whereas in East and North Herts CCG's area, there are some appropriate day care settings.**

### **18 - 25 year olds**

The 0 - 25 Service is so named because it is supposed to consider the needs of children and young people who are aged 0 - 25 years. Some of the young people aged over 18 with high medical needs who leave Nascot Lawn are placed out of County in full time residential settings. This is very expensive to Hertfordshire County Council. There is no nurse led respite service for 18 - 25 year olds in Hertfordshire. Any future service proposals should consider the overnight respite needs of young people aged between 18 - 25 years this may allow more young people with high medical needs to stay at home, this would save Hertfordshire County Council money and would save families having to make difficult 'snap' decisions based on a young person's date of birth rather than solely on their best interests.

**A time line for the development of an 18 - 25 service should be agreed by Scrutiny as part of this process.**

### **3 How will the integration and joint responsibilities between HVCCG and the County Council be arranged and managed going forward?**

#### **Transition support**

We, the Nascot Lawn families, have been the ones who have borne the full brunt of HVCCGs ultra vires and destabilising decision to halt a process of transitional talks and announce the cut in funding for Nascot Lawn. Many families are now receiving as little as 25% of the agreed allocation of respite care in their care packages as a direct result of this action. Many are just about coping, some are not: We have requested that some families receive emergency support from the County Council because they are breaking down. The impact on siblings' mental health and school grades has been particularly distressing to note. Siblings, young carers, have one chance to sit their SATs, their 11+, their GCSEs and having severely reduced respite support means they have suffered as their parents have to spend more time managing their disabled child and less time supporting revision or providing a quiet place to work.

Whatever is agreed as a future plan for respite, **Nascot Lawn should remain open until all of its families have successfully transitioned to a new setting and are in receipt of their allocated care package. We believe this may take until March 2020** (as building works and other arrangements take time) and an explicit funding commitment should be sought by Health Scrutiny until this date to allow the provider to plan the service and recruit staff.

#### **The 'lost' children**

New children have not, with a couple of exceptions, been admitted to Nascot Lawn since the first decision by Herts Valleys CCG to close the centre. We are very concerned that children who would previously have been judged eligible to attend Nascot Lawn are being 'lost' in the uncertainty created by this decision because paediatricians and other professionals have nowhere to refer them to. An account drawn from an interview with one such family follows:

"Summer time was relatively uneventful with the child having her usual seizures but nothing that warranted hospital. From September, the child's seizures started getting worse and worse with admissions ranging from every two weeks to every two days until she was finally admitted to Great Ormond Street's Koala Ward High Dependency Unit over the Christmas holidays. Life was tough in between and still on-going today. The child had another admission on Sunday 4 March for seizure exacerbation. The child's health has deteriorated meaning there is no predicting her response to rescue medications; there is no continuity. The family cannot plan anything, have cancelled trips/holidays, and Christmas

was cancelled. This is all having a massive impact on the family.

The child has qualified for Children's Continuing Healthcare. The child's mother has spoken to social services about a care package but is unclear what exactly that will be and when it will commence.

The child has been referred to West Hyde by her paediatrician but it is unclear when she will be accepted. The family have been told this referral to West Hyde is because of the uncertainty around Nascot Lawn. The child's response to rescue medication varies from visit to visit. It means that only professionals that know the child should be handling her secondary care."

Families and professionals urgently need clarity on where high medical needs children can be referred to - some of their situations are urgent. Amongst other families we have spoken to, there are children with life limiting conditions whose position is deteriorating, they cannot wait for a decision to take its course. We ask Health Scrutiny to require the CCGs and County Council to lay out a referral pathway for professionals who wish to refer families to existing respite services in and out of County. We also believe a full survey of relevant professionals should take place before new services are designed and capacity considered because there is no current information on how many high medical needs children are not known to respite centres.

### **The details matter**

Throughout this process the families have been in touch with each other as best we can, but we know that we are not reaching all of the families who use Nascot Lawn through our informal groups. From the 30-40 families we are reaching, we are hearing that as transition to new settings takes place, some families are getting different allocations from panel than others, some families receive a lot of contact from family practitioners, others have none.

We believe that fewer than 10 children since the original announcement in May / June 2017 have actually managed to have their care allocated to another respite centre. Even this is not an equivalent level of care. One child with complex health needs has had their care successfully transferred to an out of county hospice. Other children who need emergency respite are ending up spending extended time in hospital to allow their families respite - which Herts Valleys CCG assured Health Scrutiny and the parents would not happen. Some 'Shared Care' arrangements (where a trained foster carer provides families with support in their own home) have broken down, one family said, "[Shared Care] has now been pulled so my child no longer attends any setting outside of home, unless myself or a nurse is present... This means my child cannot stay [independently] overnight anywhere at the moment except Nascot Lawn". We have been explicitly encouraging families to make progress with transitioning to other respite facilities as quickly as possible - but we ask Health Scrutiny members to look at how little has been achieved in the past 9 months. Please don't be fooled that changes to respite can be made quickly.

**Getting the transition right, getting the details and communication right and giving your County officers adequate resources to do this job well is vital. Children are falling through the administrative gaps - the details of what is happening to each family matters.**

### **Conclusion**

Our evidence makes it clear that not enough progress has yet been made for our families to be confident that their children are going to receive respite care that is equivalent to that currently offered by Nascot Lawn.

We ask members of Health Scrutiny Committee to consider carefully the principles we have laid out for any alternative service offer.

**The people who run the NHS in Hertfordshire, and our County Councillors, speak of putting the care of our children first. But it is time for action not words. Nascot families have been pushed around for nine months, and many are at breaking point. Today we call upon the NHS in Hertfordshire and our County Councillors to commit to funding Nascot Lawn until March 2020, giving all parties enough time to develop and implement a sustainable plan for respite care in the County.**

It is particularly important for those families whose children have very high medical needs. They should be first in the queue, not treated as an afterthought. As one foster carer said of her high medical needs child:

“Overnight respite is not a luxury it's a necessity. Without it this child may well have to go into residential care which would be devastating for him. He had a dreadful start in life and we are the only stability he has ever known, we want to be able to continue to care for him.”

Please don't accept any proposal that cuts our respite care, puts the most vulnerable to the back of the queue or puts us under such pressure that we are no longer able to cope. As a County, as health care providers, as responsible Councillors, you have a duty to support families like ours who give all we can to keep our children at home.