

## Health and Adult Social Care Select Committee

15 November 2012

### Short breaks services in West Sussex for children with complex health needs and disabilities

#### 1. Executive summary

- 1.1. NHS Sussex is working with Sussex Community NHS Trust, West Sussex County Council and with families to review how the NHS makes short breaks available to support families who have children with complex needs and disabilities.
- 1.2. A short break can include day, evening, overnight and weekend activities and can take place in the child's family home, the home of an approved carer or in a residential or community setting. This was previously known as 'respite care'.
- 1.3. Short breaks will continue to be provided for children and their families. There are well-recognised reasons to provide short breaks and their efficacy is supported by a strong body of evidence. Short breaks provide positive activity for each child in addition to that available to them in at home either in the form of leisure and/or preparation for adult life. Short breaks also provide a break from caring for parents. This affords the opportunity to rest, physically and emotionally, and undertake activities either alone or with the disabled child's siblings. In this context the extra stresses of caring for a disabled child or young person are recognised.
- 1.4. NHS-led residential short breaks in West Sussex are currently provided at three units: Holly Lodge in Horsham, the Cherries in Chichester and Finches in Burgess Hill (Finches is part of Chailey Heritage Clinical Services). These units are managed and operated by Sussex Community NHS Trust. The services are commissioned on behalf of NHS Sussex, by the Children and Families Team, within the West Sussex Joint Commissioning Unit.
- 1.5. We need to plan for change because two of these three centres, The Cherries and Holly Lodge, currently only take children who are eligible for full NHS continuing healthcare funding. This year there are fewer children using these two centres than in previous years and the numbers will continue to fall further. This is due to a combination of family choice and national changes in funding. The third unit, The Finches, is jointly funded by health and social care.
- 1.6. This paper sets out the national and local context for provision of short breaks to children with complex needs and disabilities. It builds on discussions with parents and other stakeholders such as special schools in the area. The paper outlines initial consideration of options for change to ensure we have a sustainable short breaks service.

## **2. Recommendation**

- 2.1. The Health and Adult Social Care Select Committee are asked to consider the initial proposals to:
- involve parents and stakeholders in shaping the future of the short breaks service
  - invite detailed business cases for redevelopment of The Cherries and Holly Lodge as part of a jointly funded partnership model
  - transform the children's community nursing service in line with national best practice to support training and education in the needs of children with complex health needs and include a rapid response team to provide continuing care to technology-dependent children and children with end-of-life needs as part of an integrated pathway of out of hospital care for children
- 2.2. At this stage NHS Sussex does not consider the options in this paper as the basis for consultation. They are initial options for change to facilitate discussion with stakeholders. It is likely that more detailed options for change will be developed following further exploration of option 3.

## **3. Current short break services**

- 3.1. NHS Sussex is working with Sussex Community NHS Trust and with families in West Sussex to review how the NHS makes short breaks available to support families who have children with complex needs and disabilities.
- 3.2. A short break can include day, evening, overnight and weekend activities and can take place in the child's family home, the home of an approved carer or in a residential or community setting.
- 3.3. Short breaks will continue to be provided for children and their families. There are well-recognised reasons to provide short breaks and their efficacy is supported by a strong body of evidence. Short breaks provide positive activity for each child in addition to that available to them in at home either in the form of leisure and/or preparation for adult life. Short breaks also provide a break from caring for parents. This affords the opportunity to rest, physically and emotionally, and undertake activities either alone or with the disabled child's siblings. In this context the extra stresses of caring for a disabled child or young person are recognised.
- 3.4. NHS continuing care is support provided for children and young people under 18 who need a tailored package of care because of their disability, an accident or illness, and have been assessed as eligible for NHS continuing care. A range of organisations will work together to put the child's care package into place – this may include health, education and local authority children's services. The process of arranging NHS continuing care is led by the Commissioner

- 3.5. In West Sussex short breaks are available in a number of settings including the child's own home. It is estimated that 90 families with children with complex needs and disabilities in West Sussex are supported with short breaks funded by the NHS.
- 3.6. The units and current number of NHS funded children in each unit are as follows:

| Unit                             | Operated by                | Numbers of children with NHS funding |
|----------------------------------|----------------------------|--------------------------------------|
| Holly Lodge                      | Sussex Community Trust     | 6                                    |
| Cherries                         | Sussex Community Trust     | 17                                   |
| Finches                          | Sussex Community Trust     | 9                                    |
| West Sussex County Council Units | West Sussex County Council | 6                                    |
| Chestnut Tree House              | St Barnabas Hospice        | 4                                    |

- 3.7. Two units in West Sussex only provide breaks for children who are eligible for full NHS funding - Holly Lodge in Horsham and The Cherries in Chichester.
- 3.8. West Sussex has an NHS funded Children's Continuing Care Service (CCCS). This service is an outreach nursing care service involving children's nurses and skilled children's healthcare workers who provide care and support in a child's home throughout the day and night, often in addition to other support arrangements.
- 3.9. West Sussex County Council have three residential homes for children with complex needs and disabilities in the county which offer short breaks.
- 3.10. More detail of each current service including numbers of beds is in Appendix A. The maps in Appendix B show the current configuration of short break units and the geographical distribution of the take-up of residential short breaks.

#### 4. The case for change

##### 4.1. National eligibility criteria

- 4.2. Recently there has been a change in national criteria in the Framework for Children's Continuing Care (Department of Health, 2010), which has affected the number of children who are eligible for full NHS funding. This is affecting children who are currently accessing services and children who are being referred for funding. Overall, it is reducing the number of children who are eligible for NHS funded Continuing Care. There were 110 active cases in 2010/11 and there are currently 86 active cases at this point in 2012/13.
- 4.3. This national change in eligibility is having a direct impact on the NHS funded short break units in West Sussex and is significantly reducing the number of families using these services. Furthermore, in terms of future needs and demands, Dr Youngman concluded (as part of a local review of services for children in West Sussex with complex health needs was completed in 2011 see Section 4.8) that it is likely that the number of children with complex needs will not increase and that there will be a greater increase in the prevalence of children with disabilities who have mild to moderate needs. Birth rate will be the

key driver for any increase in children with very complex health needs. In West Sussex, despite earlier expectations, the Birth rate has only risen by 1.5% between 2010/11 and 2011/12. This is lower than the national average of 5%. See Appendix D. It is important to note that additional analysis of the impact on the child disability services is also therefore required.

4.4. National policy and best practice

- 4.5. In addition to the eligibility process, there has been a new vision set by the Department of Health for children with nursing needs in the community. The national vision is to transform children's community nursing services to improve the experiences of children, young people and their families. This is set out in a model called *NHS at Home*, which outlines how integrated teams should provide a range of care for children with health needs and their families, from support in their home to expert supportive care in hospital to specialised respite care. It describes how a comprehensive service should enable effective community nursing for children and help their transition into adult services. The *NHS at Home* model recognises the need for care in various settings and includes care provided outside of the home.
- 4.6. There is wide take-up in West Sussex of the direct payments scheme for social care. Direct payments aim to give families more flexibility in how services are provided. Families have greater choice and control, and are able to make their own decisions about how care is delivered for their child. Many families receiving direct payments are moving away from using traditional overnight care units.
- 4.7. There are some new and more innovative ways of organising and providing short breaks including new initiatives that were set up through the Aiming High for Disabled Children programme from 2008-2011. The new statutory duty to provide short breaks commenced in April 2011 and a wide range of short breaks services are now in place across the county. Any disabled child receiving middle or high rate care component Disability Living Allowance can access these services without needing a social care assessment. With the emphasis on inclusion and an "ordinary family life", short breaks for children are moving away from the traditional overnight care units. However, there will always be the need for overnight short breaks to be provided for some disabled children, particularly those with complex health needs and where lack of sleep is a significant issue.
- 4.8. Local challenges
- 4.9. The NHS funded services for continuing care are operated by the provider organisation SCT. In the last 18 months the Provider has approached Commissioners in the NHS and the County Council with concerns that the current configuration, funding and uptake of the short breaks units has become unviable at current levels of referrals and funding.
- 4.10. In addition there have been significant challenges over the past few years in recruiting registered children's nurses due to the perceived uncertainty of the future of these units and a national shortage of registered children's nurses. Instability of the workforce necessitated a comprehensive risk assessment by SCT in August 2012 and a resulting change in provision to ensure safety and sustainability for the current children and families accessing the services. Holly

Lodge has been temporarily closed with children moved primarily to the Finches and Chestnut Tree House, staff have also moved to the Finches and the Cherries.

4.11. Local review and planning

4.12. A local review of services for children with complex health needs was completed in 2011 in conjunction with Dame Philippa Russell of the National Children's Bureau. This report sets out current services and how these should be developed to further improve what is available for children and their families in West Sussex. Philippa Russell completed an extensive process of engagement and consultation (including workshops, one to one interviews and surveys) with families as part of that review. The report concluded there are opportunities to consider more domiciliary support to families rather than using residential provision that is distant from the child's home. However, children with continuing healthcare needs will require trained staff, with access to specialist advice and support if necessary. Some families want overnight residential provision in order to give time to other children or family members. Therefore, it is important to retain some strong and high quality residential core service. She concluded that more flexible services needed to be provided for children with complex needs than only traditional institutional based respite care. See Appendix C for more detail of this review.

4.13. In November 2011 Children's Continuing Healthcare and West Sussex County Council Child Disability Team (CDT) agreed to jointly fund care packages where children meet the continuing care criteria. This is being implemented as reviews and referrals are presented to continuing care, establishing joined up funding as recommended in the National Framework for Children and Young People's Continuing Care (DH 2010).

4.14. The direction for services across the country establishes the need for change, irrespective of the current eligibility situation, as this new vision for services would need substantial service redesign to ensure successful implementation in West Sussex.

**5. Options for change**

5.1. The factors described above mean there is an urgent case for change in local short breaks services. In order to facilitate discussion, the short breaks programme board has set out three initial options. Feedback on these options will inform the development of more detailed plans to ensure safe and sustainable transition.

5.2. Option 1: Do Nothing

5.3. The current short break services would continue to be run for a small number of children and young people with disabilities. Costs per individual child would escalate as numbers reduce further due to family choices and national eligibility criteria. There would be no opportunity for investment in a new Community Children's Nursing Service that is based on national best practice.

The Short Breaks Project Board (see paragraph 7.4) has confirmed that this option is not viable as it is not clinically or financially sustainable in the long term.

- 5.4. Option 2: Transform the existing service to implement a new Community Children's Nursing Service that is based on national best practice as described in NHS at Home (DH 2011)
- 5.5. This option would establish a new comprehensive children's community nursing service in line with the *NHS at Home* model. The support packages for eligible children would be maintained by providing care or accommodation in alternative services.
- 5.6. This option would mean phased a transformation process for Holly Lodge, the Cherries and the Children's Continuing Care Service as they become part of the new service. It is likely that the buildings would close, but the existing workforce would be preserved in numbers to help to deliver the new model of service, including the recommended ratio of children's community service to child head of population. If under option 2 current units are closed, travel times for existing families to new short break facilities and support will need to be considered. However, travel times to residential short break units - for many new and existing children and families – may not be as relevant as more support is provided closer to home. In addition, services will be provided in areas that do not currently have facilities. Therefore the key question is not only: what additional travel time there will be for families under this option, but also how much travel time is saved under the new arrangements.
- 5.7. As part of this option the national best practice *NHS at Home* model would be implemented in West Sussex. Further details of what this model are included in Section 6.
- 5.8. Option 3: Invite providers to develop new short break services in partnership, utilising all or part of the existing buildings
- 5.9. This option has been included in recognition of the new agenda for continuing care services that are local to need, reflect personal choice and embrace non-statutory income and social entrepreneurship.
- 5.10. There would need to be some investment to upgrade the existing service offer with a view to extending the service to a wider range of children to provide a varied short break. The upgraded service would have to be financially and clinically viable, and would require experienced management.
- 5.11. The Children's Continuing Care Service (CCCS) and Community Children's Nursing team would integrate as part of beginning the implementation of the *NHS at Home* model in West Sussex.
- 5.12. This option would involve new provider(s) gaining additional income streams but also maintaining the availability of residential short breaks in the current geographical spread across the county.

- 5.13. The current provider of services at Holly Lodge and The Cherries, SCT are clear that they cannot sustain the services at Cherries and Holly Lodge indefinitely. It is therefore suggested that a business case and viability study for option 3 needs to be presented by potential providers by the end of December 2012 so that a decision and planned transformation can be in process by April 2013. The commissioners would support potential providers in developing their business case, for example by clarifying demand and clinical requirements.

**6. *NHS at Home* model**

- 6.1. Options 2 and 3 facilitate the transition to the nationally recognised best practice described in the 2011 Department of Health review of community children's nursing services, *NHS at Home*. This document sets out how Commissioners and Providers need to develop services to further improve what is available for children with complex health needs and their families. The NHS at Home model recognises the need for care in various settings and includes care provided outside of the home.
- 6.2. The recommendations ensure that the needs of ill and disabled children are met, in particular in relation to four groups of children and young people who have been identified as needing services with:
- acute and short-term conditions
  - long-term conditions
  - disabilities and complex conditions, including continuing care and neonates;
  - life-limiting and life-threatening illness, including end-of-life care
- 6.3. Community children's nursing services are the essential foundation of the pathways of these children's care. It is widely accepted this is the vision and direction of travel for services across the country for these children and their families. A Children's *NHS at Home* service would be a countywide team established to meet the needs of children of the above four groups.
- 6.4. The establishment of the new service will begin with the service re-design for children with long-term conditions, complex needs and disabilities. This re-design will be undertaken jointly with the County Council Child Disability Service, disabled children, young people and parent carers.
- 6.5. Children's community nursing locally will offer high quality, effective and equitable nursing and healthcare to enable disabled children and young people with complex health needs to actively participate in day, evening or overnight short breaks in West Sussex. Under Option 2, service will change but not be diminished. Support to children and families will continue.
- 6.6. This is including the provision of an integrated and flexible service which promotes an individualised package of care for disabled children, young people and their families, whilst recognising that a short break forms part of a wider care plan. The service will provide training and advice to staff in residential short break and other community settings to promote the inclusion of disabled children and young people with complex needs.

**7. Engagement to date**

- 7.1. West Sussex review of services to children with complex needs, 2011
- 7.2. This survey of views by questionnaire, workshops and interviews, contacted all families with NHS funded continuing healthcare and those with a wider range of disabilities through the West Sussex Parents Forum. Key to this work was the finding that parents wanted a menu of short breaks options from sitting services through to overnight care. There was limited use of domiciliary care but interest in developing more of a day care role in residential units. For more detail see Appendix C.
- 7.3. Short breaks project board
- 7.4. The project board, which has been meeting regularly since September 2011, was established by children's commissioners in the West Sussex JCU and all the main stakeholders are represented including West Sussex County Council CDT managers, SCT managers, the West Sussex Parents Forum and third sector providers such as Chestnut Tree House.
- 7.5. It is a clear priority for the project board to ensure parents are engaged throughout the development of the options and as the project moves forward towards a decision.
- 7.6. To date there has been direct engagement with parents of the children currently using both Holly Lodge and The Cherries. This has focused on both the current operational issues and the longer term need to review services and look at the options for providing care to them in the future.
- 7.7. The project board has met and agreed on the options outlined in this paper and that option 1 is not feasible. It is now meeting on 4 – 6 weekly basis to take the project forward.
- 7.8. Lead members of the project board from NHS commissioning, NHS provider and West Sussex CDT have met directly with parents from The Cherries and have regular meetings arranged. A meeting has also been arranged with Holly Lodge parents.
- 7.9. Staff involvement
- 7.10. Discussion have been held with staff working in the short breaks units; CCCS and Community Children's Nursing team focussing on the need for change. With the recent operational changes there has been an increase in staff engagement which has also been used to facilitate discussion about the options for change and how services may change in the future.
- 7.11. Parents and families
- 7.12. Clinical management teams on each site have provided information and support on a day-to-day basis for the families using the units.
- 7.13. Parents of children who used Holly Lodge have individually met with SCT Head of Children's Community Nursing Services, Trudy Ward. It has been reported to the Project Board that there is a general satisfaction expressed with the



alternative short breaks service provided at the Finches in Burgess Hill, where most children have been transferred to. A meeting is planned with parents and stakeholders to update them regarding Holly Lodge and to share ideas and visions for a new service.

- 7.14. At The Cherries, the staffing situation has been stabilised as Holly Lodge staff have temporarily joined the team. All parents of children at the Cherries have been contacted by SCT staff. A group of parents at The Cherries have been very active in setting up an online petition, talking to the media and writing to their MP to raise their concerns over the potential closure of The Cherries. This group have expressed concerns about the travel implications of any closure plans as they would want to continue to have overnight breaks for their children. Regular monthly meetings with parents have been established to ensure information is shared and parents concerns are heard.
- 7.15. Holly Lodge neighbours Queen Elizabeth II School, which caters for up to 70 children with severe or profound and multiple learning difficulties. The Head Teacher of the Queen Elizabeth II School, Lesley Dyer, has been central to early planning for the development of an alternative service under the option 3. The Head Teacher of Fordwater School, Sue Meekings, is also involved in developing a vision for option 3. Fordwater School caters for children with severe and complex learning difficulties and is adjacent to The Cherries.
- 7.16. Both parents and staff generally accept that services cannot continue in the same way and are unsustainable. However there is concern about losing the units and, for parents especially, the familiarity these units have with their children. It is important to consider both current and future service users when deciding on the future models of services to these children.
- 7.17. It is important to note that there has been engagement with children and families over recent years focused on the future of services locally. As outlined in Section 4.8 and Appendix C, with the support of external experts - such as the National Children's Bureau – feedback and insights have been gained by commissioners and providers on what customers feel works well and what does not. In particular, the views of current families have been captured as well as how need and demand will change over time.

## **8. Resource Implications and Value for Money**

- 8.1. The short breaks units operate on a cost-per-case tariff which is a flat nightly rate. As the numbers accessing the units have reduced, the cost becomes higher for each remaining child affecting the viability of the service. In addition the reducing numbers of children has compromised the operational and clinical sustainability of the service.
- 8.2. Since November 2011 Children's Continuing Healthcare and West Sussex CDT have been jointly funding care packages, initially under a funding matrix that was developed in Oxfordshire and now splitting all funding equally. This is being implemented as reviews and referrals are presented to continuing care, establishing joined up funding as recommended in the National Framework for

Children and Young People's Continuing Care (DH 2010). This is proving a cost pressure to the CDT and work is underway to quantify this.

- 8.3. In addition the need for overnight short breaks care for children who no longer meet continuing care criteria is having a significant impact on the three West Sussex County Council units that provide short breaks. This is particularly the case for Cissbury Lodge in Worthing because of its geographic location and because it is the only one of the three which can meet the needs of children with significant physical disabilities.
- 8.4. The continuing care at home team (CCCS), operated by SCT, will be included in the West Sussex *NHS at Home* model and will provide a rapid response care package for children who are technologically dependent as well as end-of-life patients. This will be better use of the team's expertise and of resources.
- 8.5. We are now in a position where we need to consider sustainable options for the future. As laid out in the evidence so far, it is clear that short breaks need to continue to be provided for children and their families but a different way.
- 8.6. The commissioners are clear that there is adequate capacity for overnight breaks without The Cherries and Holly Lodge. Although the geographical spread of overnight services will be less even (see Appendix B), there will still be overnight breaks provided for children with complex health needs at The Finches in Burgess Hill, Cissbury Lodge in Worthing and Chestnut Tree House Children's Hospice for children with life-limiting disorders near Arundel. The West Sussex *NHS at Home* model of children's nursing will provide additional specialist training for staff in settings where children with complex health needs receive short breaks.
- 8.7. The Holly Lodge and The Cherries buildings are owned by NHS Sussex and leased to SCT. Unless otherwise agreed, on 1 April 2013 the buildings will transfer to NHS Property Services, the organisation set up by the Department of health to manage NHS estate following the closedown of PCTs.

## **9. Risk Management and Direction of Travel**

- 9.1. The risks associated with the options are summarised below.
- 9.2. Option 1 – Do Nothing. Services will continue for existing children and families. However, numbers will continue to fall resulting in an increase of cost per child, impacting on NHS funded continuing care being able to support other children. The services will find it increasingly difficult to attract registered nurses and healthcare staff leading to the services eventually closing anyway. The opportunity to create an alternative, integrated and innovative service in the buildings could be lost.
- 9.3. Option 2 – Transform the existing service to implement a new Community Children's Nursing Service that is based on national best practice as described in *NHS at Home*. There would be a loss of residential provision for overnight short breaks in the current units in Horsham and Chichester, but the continuation of short breaks provision for children and families in other forms. The unit buildings

are both next to – or sited on - a special school campus, this proximity of service to schools would be lost as well as geographical spread. Support to families and residential short breaks would still be available elsewhere in the county.

- 9.4. Ensuring there is flexible and sufficient levels of capacity and support to families will require further more detailed analysis and planning.
- 9.5. Option 3 – Invite providers to develop new short break services in partnership, utilising all or part of the existing buildings. A robust business case would need to be developed that evidenced viability and identified costs and potential revenues. Funding from NHS continuing care is limited by the eligibility criteria. Social Care led services already have four residential homes for children with complex needs and disabilities in the county and are not planning to extend their service provision. The development of new services in partnership (option 3) is dependent on collaboration between providers to devise a service that can be commissioned. To ensure the sustainability of services at The Cherries and Holly Lodge a business case and viability study would need to be presented by the end of December 2012 and a decision and planned transformation should be in process by April 2013. There are two key risks: can additional non-NHS funding be obtained by the new provider(s) and can the units still maintain the standards required by the Care Quality Commission to enable them to provider health care services.

## **10. Ensuring the opportunity for short breaks in West Sussex**

- 10.1. Short breaks would still be available to children and their families across West Sussex in each of the options outlined in this document.
- 10.2. There are well-recognised reasons to provide short breaks and their efficacy is supported by a strong body of evidence. Short breaks provide positive activity for each child in addition to that available to them at home either in the form of leisure and/or preparation for adult life. Short breaks also provide a break from caring for parents. This affords the opportunity to rest, physically and emotionally, and undertake activities either alone or with the disabled child's siblings. In this context the extra stresses of caring for a disabled child or young person are recognised. There is also a statutory duty to provide short breaks.
- 10.3. Short breaks are a form of family support without which it is possible that there would be more family breakdowns and more children being taken permanently into care. The term "short break" encompasses a wide variety of short break models from those providing a few hours break, to a few days, or even longer in a residential or holiday setting.
- 10.4. Some families may wish to alter the support they receive and take up different options – a personal budget for example – and this will supported by the organisations involved in their care. Overnight breaks will remain in the menu of short breaks offered, although as they are an expensive option for a personal budget some parents are choosing to spend the budget on different forms of support. It is unlikely (given the emerging evidence from other authorities) that providing parents with personalised budgets will mean that the Units become viable through customer choice and preference.

- 10.5. Every family is different and we will continue to work with each family individually to address their needs.

## **11. Recent temporary closure of Holly Lodge**

- 11.1. At the end of September 2012, in response to a shortage of the highly skilled and experienced staff needed at both Holly Lodge and The Cherries and a significant reduction in children accessing Holly Lodge, a decision was taken by SCT in discussion with NHS Sussex to close Holly Lodge as a short term solution. SCT worked closely with the eight families who were using Holly Lodge and transferred the children's breaks to the Finches in Burgess Hill, and staff to the Cherries and the Finches.
- 11.2. The temporary closure of Holly Lodge is an operational decision which is separate from the process of developing options for change to ensure we have a sustainable short breaks service. Appendix D shows a letter from the SCT Director of Operations which provides further details of the temporary closure.

## **12. Next steps**

- 12.1. Any timetable is of course dependent on the decision of the local health and social care scrutiny process. The options in this paper are intended to facilitate discussion on the way forward rather than form the basis of consultation at this stage.
- 12.2. SCT, the current provider of services at Holly Lodge and The Cherries, has indicated that to maintain a safe and sustainable service clear plans for change should be agreed by April 2013.
- 12.3. Feedback from parents and other stakeholders has indicated interest in exploring further Option 3 - inviting providers to develop new short break services in partnership, utilising all or part of the existing buildings. It is suggested that a business case and viability study for option 3 needs to be presented by potential providers by the end of December 2012 so that a decision and planned transformation can be in process by April 2013. The commissioners and the existing provider would support potential providers in developing their business case, for example by clarifying demand and clinical requirements.
- 12.4. The services commissioned in this report are health responsibilities and current and future budgets for continuing health care for children and young people will continue to be NHS responsibilities. NHS Sussex is the decision making body until April 2013 and will involve the local Clinical Commissioning Groups across West Sussex which will be formally responsible from April 2013.

- 12.5. The Short Breaks Project Board is planning further opportunities for parents and children to be involved in shaping the service. A local implementation group for the *NHS at Home* initiative will be set up by the Children's and Families Joint Commissioning Unit for parents and children to be involved in that process.

**Aaron Gain** - Principal Manager Children and Families, Joint Commissioning Unit, NHS West Sussex and West Sussex County Council

**Gillian Wieck** – Assistant Director of Operations Children, Health and Reablement and Wellbeing, Sussex County NHS Trust.

**Jon Philpot** - Principal Manager (Specialist & Disability Services, Children's Services, West Sussex County Council

### **Appendices**

**Appendix A** – Profile of services

**Appendix B** – Maps showing distribution of families using short breaks units

**Appendix C** – West Sussex review of services to children with complex needs 2009 – 2011

**[Appendix D](#)** – Letter from Sussex Community NHS Trust to Margaret Whitehead, Chairman of the Health & Adult Social Care Select Committee, on Changes to Children's Short Breaks in West Sussex

### **Background Paper**

The West Sussex Review of Services to Children with Complex Needs 2009-2011

## **Profile of services**

### **The Cherries**

This unit is located in Chichester, near to the Fordwater Special Needs School. It is a five bedded unit that is open for 4 nights a week. The Cherries also offers day time short breaks during weekdays, weekends and holidays.

In October 2011 there were 24 children using The Cherries (21 for overnight short breaks) and the unit changed from being open 5 nights a week to 4 nights a week. In October 2012 there were 21 children using the unit (18 for overnight breaks) requiring 913 nights per year. It is anticipated that this number will fall by the end of 2012 as young people transition to adult services and current children may not be confirmed as eligible for future funding. The total overnight capacity is approximately 1,775 nights per year.

The Cherries is funded on a “nights per patient per annum” basis, costed on a flat nightly tariff which has remained the same for more than three years. The Cherries also provides day care on a half-day or hourly rate. The Cherries is 100% NHS funded and is – in the main – wholly commissioned by the Children’s Specialist Nurse for NHS Continuing Healthcare (CHC commissioner) in the West Sussex Joint Commissioning Unit (the Commissioner). There is nothing in the conditions on the building which would prevent funding from other sources.

The Cherries is managed by Sussex Community NHS Trust.

### **Holly Lodge**

This unit is located in Horsham on the same campus as the Queen Elizabeth II Special Needs School. It is a five bedded unit which usually also offers day time short breaks during weekdays, weekends and holidays.

In October 2011 there were 14 children accessing the unit and opening nights were reduced to 4 nights per week from 5 because of the reducing numbers of children. In October 2012 there were 8 children accessing the service requiring 420 nights per year. This number fell during 2011/12 because young people left the unit as they moved into adult services, and also due to the 2010 eligibility criteria changes. The total overnight capacity is approximately 1,775 nights per year.

Holly Lodge temporarily closed at the end of September in response to a shortage of the highly skilled and experienced staff needed.

Holly Lodge is funded on a “nights per patient per annum” basis, costed on a flat nightly tariff which has remained the same for more than three years. Holly Lodge can also provide day care on a half-day or hourly rate. Holly Lodge is 100% NHS funded and is – in the main – wholly commissioned by the Children’s Specialist Nurse for NHS Continuing Healthcare (CHC commissioner) in the West Sussex Joint Commissioning Unit (the Commissioner). There is nothing in the conditions on the building which would prevent funding from other sources.

Holly Lodge is managed by Sussex Community NHS Trust.

Both Holly Lodge and Cherries are owned by NHS Sussex.

### **The Children's Continuing Care Service**

This service is an outreach nursing care service involving children's nurses and skilled children's healthcare workers who provide care and support in a child's home throughout the day and night, often in addition to other support arrangements. The hours of care are determined by the Commissioner in discussion with the multi-disciplinary team and the child's parents / carers.

The service is funded on the basis of a tariff which pays per child, per hour.

The CCCS is operated by SCT.

### **High Trees**

High Trees in Crawley is a 6 bed unit which provides overnight short breaks and shared care packages.

High Trees is operated by West Sussex County Council.

### **Orchard House**

Orchard House is located in Cuckfield, near Haywards Heath, and is a 14 bed unit which provides full time, overnight short breaks and shared care in two separate units.

Orchard House is operated by West Sussex County Council.

### **Cissbury Lodge**

Located in Worthing, Cissbury Lodge is a 16 bed unit which provides full time, overnight short breaks and shared care. Of the West Sussex County Council units, Cissbury Lodge is the only one fully equipped and able to look after children and young people who have significant physical disabilities and may be wheelchair dependent.

Cissbury Lodge is operated by West Sussex County Council.

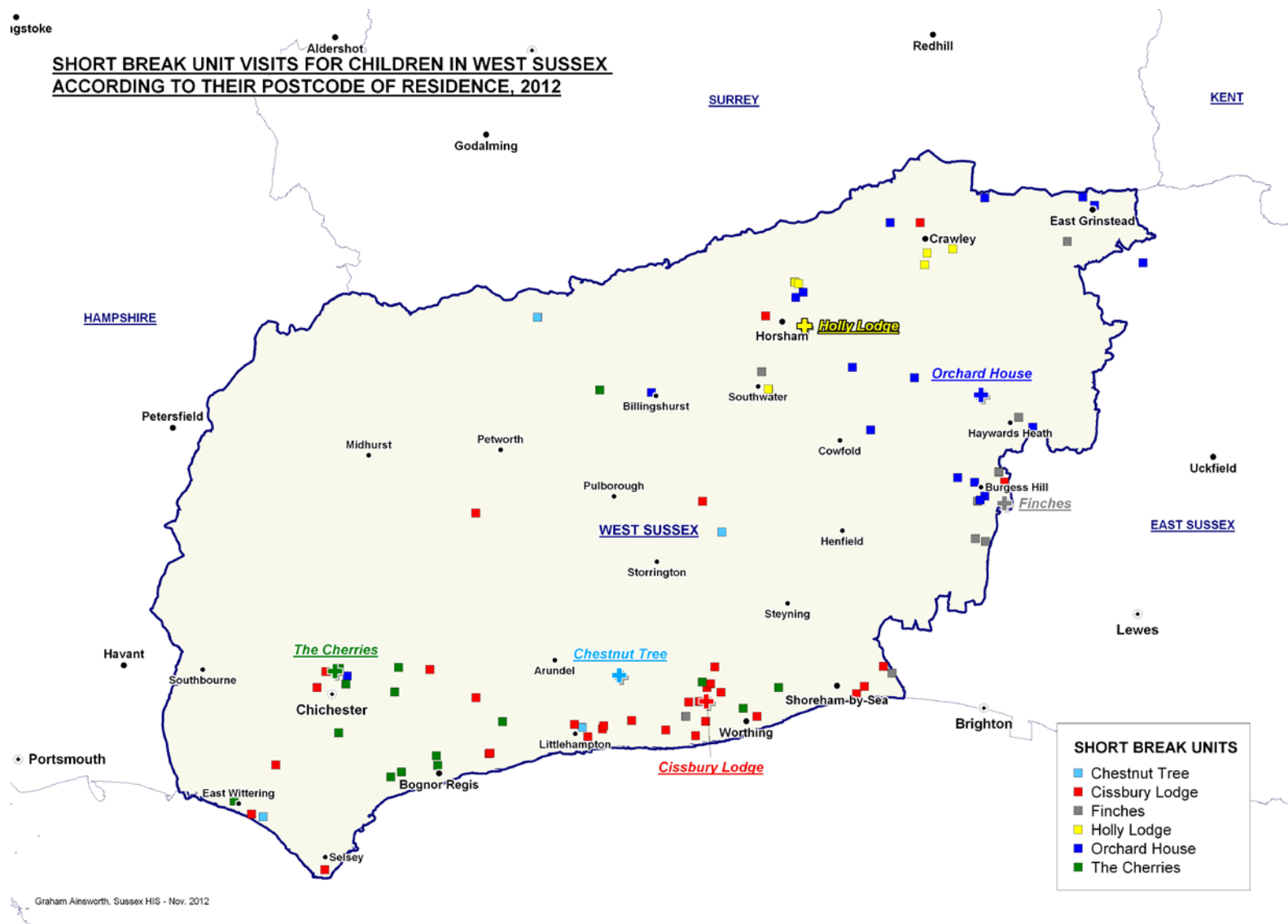
### **Chestnut Tree House**

Chestnut Tree House, located near Arundel, is the only children's hospice in Sussex and cares for children and young adults from 0-19 years of age with progressive life-limiting conditions from Sussex and South East Hampshire.

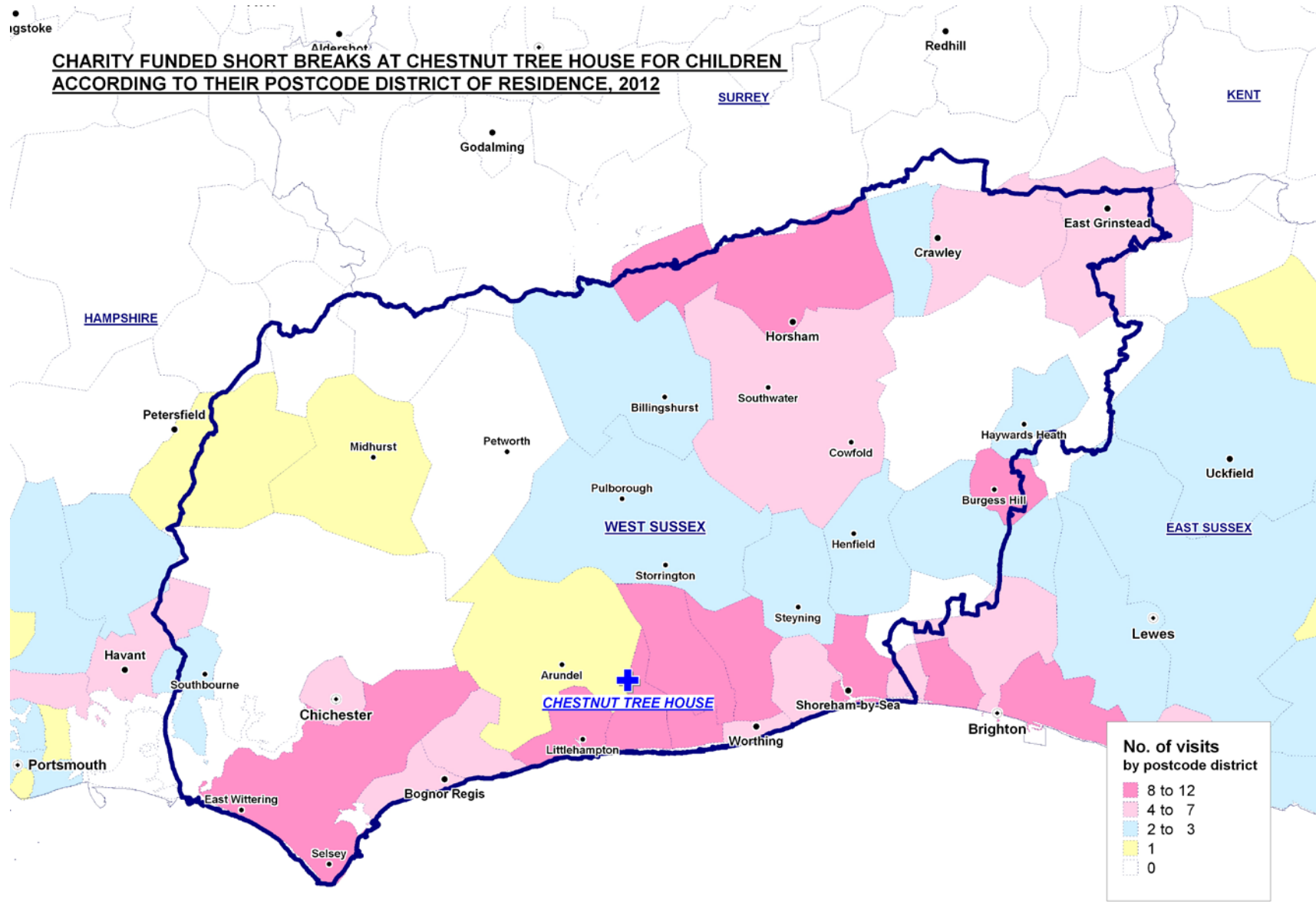
The hospice provides a 'home from home' environment with 10 children's bedrooms plus eight family rooms, a wet and dry play area, computer and music rooms, a multi sensory room and hydrotherapy pool. Chestnut Tree House offers support for the whole family including psychological and bereavement support, end of life and short break care and sibling support.

Further analysis of current capacity (both residential and other types of support) will be completed in parallel with the exploration of Option 3.

### Maps showing distribution of families using short breaks units







Graham Ainsworth, Sussex HIS - Nov. 2012

## **West Sussex Review of Services to Children with Complex Needs 2009-2011**

The review, published in February 2011, included a needs assessment and demand analysis by Dr Emily Youngman (Public Health) and a study of parent, patient/service-user and professional views by Dame Philippa Russell (The National Children's Bureau and Chair of the Standing Commission on Carers). It also includes a comprehensive review of all the other aspects of current provision and commissioning.

Dame Philippa Russell conducted a survey of views by questionnaire, workshops and interviews, contacting all families with NHS funded continuing healthcare and those with a wider range of disabilities through the West Sussex Parents Forum.

Key to this work was the finding that parents wanted a menu of short breaks options (from sitting services through to overnight care). There was limited use of domiciliary care but interest in developing more of a day care role in residential units. Parents were aware of under-use of some provision. Alternative providers, in particular Chestnut Tree House, were particularly popular with families of children with the greatest complexity - primarily due to the reported ability of Chestnut Tree House to include the whole family and the physical environment and range of activities were highly valued. One parent consulted referred to a "jigsaw", it is essential that all the pieces of the jigsaw (i.e. the multi-disciplinary team) fit together and pull together, and there is not an over-reliance on one service. There was also strong support from parents for personal budgets.

In addition, in terms of needs assessment in the future, Dr Youngman concluded that it is likely that the number of children with complex needs will only increase in line with the birth rate, and that there will be a greater increase in the prevalence of children with disabilities who have mild to moderate needs.

The report concluded there may be opportunities to consider re-focusing more on domiciliary support to families rather than using residential provision that is distant from the child's home. However, children with continuing healthcare needs will require trained staff, with access to specialist advice and support if necessary. Some families want overnight residential provision in order to give time to other children or family members. Therefore, it is important to retain some strong and high quality residential core service.