

**Service Redesign of Children’s NHS Short-breaks  
 (formerly Respite) Services**

**Governing Body meeting**

**F**

**11 January 2018**

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<b>Purpose of Paper</b>	
To provide the Governing Body with the options for public consultation for a new assessment process, resource allocation system, and service model for Children’s NHS Short-breaks provision in Sheffield.	
<b>Key Issues</b>	
<p>NHS Sheffield Clinical Commissioning Group (SCCG) has a responsibility to review the services it commissions to ensure that they provide the best outcomes for the public and patients in Sheffield and that it is using NHS funds appropriately. SCCG has a duty to meet its statutory financial obligations.</p> <p>Sheffield Children’s NHS Foundation Trust (SCHFT) is commissioned by SCCG to deliver a short-break (respite) service for children with complex and profound health needs. This is currently provided by Ryegate House Respite Unit and the Helena Nursing Service respite offer. Over the last 18 months SCCG has been working through a review of these services. The case for change reflects;</p> <ul style="list-style-type: none"> <li>• An outdated service model of short-breaks/respite</li> <li>• An inequity of provision (some families receiving high packages of care while others get nothing)</li> <li>• A drive for greater choice and flexibility for children and families</li> <li>• Drive for personalised health planning and Personal Health Budgets</li> <li>• Greater integration between health and social care</li> <li>• Financial context and the need to ensure value for money</li> </ul> <p>Following review and pre-consultation engagement, it is proposed that the current assessment and resource allocation is changed and a new service model is developed to accommodate a future provision that is more equitable, personalised and allows greater choice and control for children, young people and families.</p>	
<b>Is your report for Approval / Consideration / Noting</b>	
For approval to proceed to consultation	

<b>Recommendations / Action Required by Governing Body</b>
<p>The Governing Body is asked:</p> <ul style="list-style-type: none"> <li>• To approve the pre-consultation engagement work undertaken.</li> <li>• To approve the proposals for public consultation on the three elements of the service process and provision: <ul style="list-style-type: none"> <li>• A new single integrated and person-centred assessment (between health and social care) to assess for the eligibility for NHS short-breaks</li> <li>• A new resource allocation principle</li> <li>• Service options</li> </ul> </li> </ul>
<b>Governing Body Assurance Framework</b>
<p><b><i>Which of the CCG's objectives does this paper support?</i></b>  To ensure there is a sustainable, affordable healthcare system in Sheffield</p>
<b>Are there any Resource Implications (including Financial, Staffing etc)?</b>
<p>Management and clinical time to complete the implementation of the project</p>
<b>Have you carried out an Equality Impact Assessment and is it attached?</b>
<p>This will be completed. EIA at this stage will be based on the consultation process to ensure fully cover and wide proactive engagement.</p>
<b><i>Have you involved patients, carers and the public in the preparation of the report?</i></b>
<p>Pre-consultation engagement has been undertaken with families. This is in addition to engagement work undertaken as part of initial the review in February 2016. This has been fed into the design of the options.</p>

## **Service Redesign of Children's NHS Short-breaks (formerly Respite) Services**

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#### **1. Introduction / Background**

NHS Sheffield Clinical Commissioning Group (SCCG) has a responsibility to review the services it commissions to ensure that they provide the best outcomes for the public and patients in Sheffield and that it is using NHS funds appropriately. SCCG has a duty to meet its statutory financial obligations.

1.1 Sheffield Children' (NHS) Foundation Trust (SC (NHS) FT) is commissioned by SCCG to deliver a short-break (respite) service for children with complex and profound health needs. This is currently provided by Ryegate House Respite Unit and the Helena Nursing Service respite offer. Over the last 18 months SCCG has been working through a review of these services. The case for change includes:

- An outdated service model of short-breaks/respite
- Inequity of provision (some families receiving high packages of care while others get nothing)
- A drive for greater choice and flexibility for children and families
- The drive for personalised health planning and Personal Health Budgets
- A need for greater integration between health and social care
- The financial context and the need to ensure value for money

1.2 The approach to the review has been to involve key stakeholders in reviewing the needs analysis (including local and national benchmarking), to seek views from families that use the service and consider all potential options. Data and further exploration has shown us that:

- While the numbers of children that currently use the existing services is relatively stable, we know that the population is slowly increasing which we need to prepare for this over the coming years.
- BME communities are underrepresented in services for disabled children, this could signal there is an unmet need which a new model of provision could meet if commissioned differently.
- Sheffield allocates a comparatively high number of nights per child than other areas.
- There is a significant disparity in Sheffield between the allocation of nights in children's respite/short-breaks provision and that in adult provision
- Sheffield has a less joined up approach between the Local Authority and NHS than other areas.
- The price of the activity is high in comparison to block contracts in other areas of the country as it is based on an NHS elective bed night tariff. For example most CCGs across the country give a nominal amount to their Local Authority to deliver short-breaks to families with complex health needs. This reflects the duty

of Local Authority to provide short-breaks to families of disabled children to maintain caring role. These amounts range from £57k a year to £450K per year.

1.3 Currently there are approximately 30 children assessed as eligible to receive support from Ryegate House Respite Unit and 34 who are assessed as eligible to receive the Helena Nursing Service respite offer. There are considered to be approximately 54 families accessing a children's NHS short-breaks service. This is because some families receive both the Ryegate House and the Helena Nursing short-break offer. In addition some families have not accessed either service in the last six months. However, , there are considered to be approximately 118 children known to Sheffield Children's (NHS) Foundation Trusts who are considered to be in scope of NHS short-breaks provision now and in the future. This is because SCCG wants to expand the offer to include ventilated children and children aged under 2 years. The children in scope therefore include:

19	Children receiving a Children's Continuing Care Package
27	Assessed as eligible for the Helena Nursing Service Respite offer
8	Children aged under 2 years (not currently accessing NHS short-breaks provision)
6	Children age 3 years+ requiring ventilation (not currently accessing NHS short-breaks provision)
2	Children under 2 years requiring ventilation and receiving Children's Continuing Care Packages (not currently accessing NHS short-breaks provision)
18	Children receiving NHs short-breaks provision form Ryegate House Respite Unit
7*	Children receiving short-breaks provision form Ryegate House respite unit and have a Children's Continuing Care Package
7*	Children receiving Ryegate House Respite and provision from the Helena Nursing respite offer
4	Recent referrals to Ryegate House Respite Unit
20	Currently not in service/unmet need
118	Total

1.4 This information was provided by both the Helena Nursing Service (Lead Nurse) and Ryegate House respite Unit. This list included children who SCCG would like to include in in future respite provision e.g. ventilated children and children aged under 2 years. The children who meet criteria but don't access could be through choice but could in part reflect an unmet need. This list will not be exhaustive but provides a guide to the number of children in scope.

1.5 Sheffield CCG pays for Ryegate House Respite Unit under a set NHS national tariff based on elective bed-night costs. Under this national tariff 1-5 night stays/spells are paid via a set amount – currently priced at £1,071. This perversely means the way the 77 and 99 day package stays are structured the CCG pays the same amount (£63k per child). Based on current activity children on average only access half of their allocation. SCCG forecast is to spend around £800k in 2017/18, with an average of £608 per bed night.

5.2 The respite element of the Helena Nursing Service is commissioned through Continuing Care packages. Costs for this provision have been based on 2016/17 activity that is estimated to have cost £285k. This has been provided as part of the child's continuing care package or given as extra when nurses are freed up due to other children being in hospital. It has not been possible to currently obtain activity of Helena respite in 2017/18.

## 2. Engagement with families

Engagement with families has taken place between August and November 2017; this included an engagement event and structured telephone interviews (conducted by Sheffield Carer's Centre). The engagement questions focussed on the impact of:

- A streamlined assessment process (integrated between health and social care)
- A reduced allocation of nights
- Service options e.g. Personal Health Budgets

2.1 Out of the 54 families contacted who receive Helena Nursing Respite Provision and/or the Ryegate House Respite Service, 15 families provided feedback. There was also a set of structured telephone interviews that took place in February 2016 as part of an initial review of Ryegate House Respite Unit delivery. The findings from this have also been included within the feedback results.

2.2 The summary of feedback from the two pieces of engagement work can be found in Appendix A. However the key areas from the engagement work are:

- Families' think it is very important that NHS short-breaks provision is away from the home – 'for a proper short-break' e.g. overnight bed-based provision
- Families' think that a reduction in nights would impact on *their* ability to care for their child
- Access to emergency nights was considered very important by families
- Flexibility in how families' choose their nights was also considered is very important by families.

## 3. Proposed changes to service – the assessment and re-assessment process

Currently there are two separate assessments for each respite provision delivered by SC (NHS) FT. A joined up assessment is needed for children's NHS short-breaks provision. Families have stated through engagement that they would value a more streamlined assessment and review process. While most families would also value a single assessment process that provides one overall package of care (e.g. one package of care for all the all care packages and support the child receives). This will ensure service provision is linked across health and social care and will reduce the number of assessments that take place.

3.1 Any assessment for NHS short-breaks should primarily assess the needs of parent(s)/carer(s) and then the needs of the child. The assessment should therefore be integrated with Sheffield City Council (SCC) social care to enable them to carry out *their* statutory to provide, as part of the range of services they provide for families, 'breaks from caring for carers of disabled children to support them to continue to care for their children at home and to allow them to do so more effectively' (The Children's Act 1989). The assessment should also be personalised and outcome focused to support the drive

for Integrated Personal Commissioning (IPC) and the delivery of Personal Health Budgets (PHBs). Any provision offered to support the family and child's should consider other packages of care (Children's Continuing Care) and other offers of short/breaks and respite provision provided by Sheffield City Council and Bluebell Wood Hospice. Following assessment a 3-month review should take place to ensure provision is meeting the needs and outcomes of the child and family. Thereafter a re-assessment will take place annually or before if the child's or family's needs/circumstances change.

3.2 It is recommended that for public consultation SCCG will outline the proposal of a new integrated and person-centred assessment and re-assessment process for NHS short-breaks.

#### **4. Proposed changes to service - resource allocation system**

Sheffield benchmarks high for the nights allocated to families, with packages of 77 or 99 nights offered to families by Ryegate House Respite Unit. The average in other areas across the country is 36-48 nights, with other local authorities and CCGs allocating a maximum of 75 days a year. This is because a child staying away from the home for more than 75 days is considered a Looked After Child (Children's Act 1989 Section 20(4)) and an Independent Reviewing Officer (IRO) should be appointed. Sheffield CCG and partners have developed a resource allocation principle for children's NHS short breaks that has been considered as part of engagement work and will be part of the consultation.

4.1 SCCG proposes for consultation, that a new resource allocation principle is adopted (see Appendix B) that follows a similar banding allocation to the one proposed by SCCG adult short-breaks and would work within the threshold for Looked after Child status as discussed above. This would bring Sheffield in-line with other areas in terms of allocation of children's short-breaks and also support transitional arrangements for children entering adult services. The resource allocation principle banding system would be based on families' needs and circumstances, whilst creating a fairer system for accessing children's NHS short-breaks. In some higher exceptional and/or emergency circumstances children and families may receive over 75 days. The criteria banding levels for the provision allocation is in development and will be shaped following consultation feedback.

4.2 While this would mean that the initial offer to some families would reduce, the previous year's activity (16/17) shows that families are only currently accessing half of their nights (offered) allocation. Night stays in 16/17 ranged from 6-74 nights. Current (17/18) data also shows a similar pattern at the 6 month mid-point (September 2017). The reasons for this could be that children had been admitted to hospital and therefore were unable to access their short-break offer, families chose not to access all of their nights, and/or families don't know what their full allocation is. The engagement feedback from families has shown that many of the families currently accessing NHS short-breaks provision are unaware of their full offer including the opportunity to take-up a week's stay and the emergency nights available in exceptional circumstances.

#### **5. Service options**

A project group has been established to review the engagement findings and this is made up of members from the clinical team at Ryegate House Respite Unit, the Helena Nursing Service, and a member of Sheffield Parent Carer Forum, Local Authority short-

breaks and Social Care representatives, Children's Continuing Care, the adult CHC transition nurses and a SCCG clinical lead. This group has supported the review of the engagement findings; developed the principles for the proposed future service models; and supported the development of service options for consultation. The agreed commissioning principles are to:

- a) **Ensure patient voice and choice** – this means that parents are involved in and have a choice on what services they access and how they access them.
- b) **Quality provision which is sustainable** – a high quality service which meets the needs of the children and families and can be relied upon to provide stability and consistency.
- c) **Financially viable** – the service can be managed within the financial resources available.
- d) **Based on need and is balanced across the user groups** – The respite offered is based on need and is allocated in an equitable way.
- e) **The assessment and allocation process is clear and transparent** – parents and families understand these processes which are applied consistently to all children.
- f) **Flexible and responsive service which can support families in emergencies and where additional support is required** – families of children with complex needs can require additional support in emergency situations due to the level of needs of these children and the care required; a future service must be flexible and able to respond to this need.

5.1 The service models developed for appraisal for consultation are:

- ***Option 1 – Maintain Existing Provision i.e. commission a bed based and home-based provision from SC (NHS) FT under existing arrangements – no change***
- ***Option 2– Offer all respite through Personal Health Budgets – no commissioned service provision***
- ***Option 3 – Jointly commissioned bed based facility with Local Authority***
- ***Option 4 – Mixed model, this would involve commissioning a range of provision including bed-based, home-based and PHBs.***

5.3 Each service option has been appraised against the commissioning principles developed by the project group. For transparency SCCG proposes to outline all of the service options in the public consultation with a summary of the suitability of these options (see Appendix C).

5.4 The options for consultation are option 1, option 2 and option 4.

## 6. Next Steps

- Children's NHS Short-breaks has been identified as an Accountable Care Partnership Priority. Work will continue SC (NHS)FT and an early draft of the consultation document has been shared ,comments expected back 3<sup>rd</sup> January 2018.
- An updated draft will be shared with key partners including Sheffield City Council, Sheffield Health Watch and the Sheffield Parent Carer Forum for comment

- The consultation documentation will be finalised and will seek assurance from SCCG Patient Engagement, Equality and Experience Committee (PEEEEC) on the 15.01.2018
- The consultation will go live from the end of January/early February 2018 to allow for consultation documentation to go to print.

## **7. Action for Governing Body / Recommendations**

The Governing Body is asked:

- To approve the pre-consultation engagement work undertaken
- To approve the proposals for public consultation on the three elements of the service process and provision:
  - A new single integrated and person-centred assessment (between health and social care) to assess for the eligibility for NHS short-breaks
  - A new resource allocation principle
  - Service options

Paper prepared by Anna Clack, Commissioning Manager

On behalf of Mandy Philbin, Acting Chief Nurse

December 2017

## **Appendix A**

Summary engagement feedback with families accessing NHS short-breaks provision (from February 2016 and August-November 2017).

- Families value bed-based provision for a 'proper' short-break
- Families would choose Ryegate House Respite Unit and place value on the relationship with staff
- Most families would prefer a more streamlined assessment process (e.g. one assessment for all packages their child receives)
- Some families do not value the current home-based provision (Helena Nursing Service) that is inconsistent and often cancelled. However, those that regularly receive a consistent home respite offer value this service highly.
- Most families feel that a reduction in the allocation of nights at Ryegate House Respite Unit would impact on their ability to care for their child.
- Most families would like choice on access rather than it being prescribed by the provider
- The one week holiday is valued by those who receive it.
- Some families find individual (single) night stays difficult
- Most families could not recall having an annual assessment for NHS short-breaks since they started at Ryegate House Respite Unit
- Some families' value and benefit from Bluebell Wood Hospice respite provision. However, many families struggle to access and worry about stays being cancelled
- Families' commented that their children look forward to, have built friendships with other children and get a lot out of attending Ryegate House Respite Unit.
- An emergency night offer is important to all families. Some families have already accessed emergency nights (at Ryegate House and Bluebell Wood Hospice) while others did not know it was an offer.
- Reasons given for the need for NHS short-breaks was to improve sleep, spend quality time with their other children and catch up on jobs, all were greatly affected most of the time due to meeting the care needs of their disabled child.
- Families often haven't heard about Personal Health Budgets (PHBs) or there is little or no understanding of what it is. Some families would like more information about PHBs to support flexibility in how they use their allocation NHS short-breaks provision
- Disruption felt by some families about a night closure in August 2017 and the summer closure in 2015 (for 3 months) was raised by some families – illustrating their difficulty in coping without NHS short-breaks and short-notice cancellations. The service closed on both occasion due to staff issues.
- Preference for NHS and nurse led service rather than private sector provided service.

## **Appendix B – Resource allocation principle for Children’s NHS short-breaks**

The number of nights of short-breaks breaks should be based on supporting the family to maintain their caring role and function while considering the health needs and outcomes of the child.

To provide a clear and fair approach, we are suggesting using a banding system, in line with other areas such as Leeds. Based on what is done elsewhere, this would cover different levels of care from lower level need to exceptional and emergency needs.

We will be working up a more detailed approach with Sheffield with Sheffield Children’s NHS Foundation Trusts and Sheffield City Council which will be included as part of the consultation. This will take account of the 75 day threshold for Looked After Children’s status to bring SCCG in line with other areas nationally. It will be based on offering a personalised approach and providing an equitable and consistent framework for allocating short breaks. Allocations will take into account family circumstances including family arrangements and the health needs of main carers and siblings, as well as the level of care needed to support the child’s health needs.

For example, a higher level of nights allocation might be based on factors such as:

- Family carer having an identified health needs and little or no extended family and support
- Conditions that require 24 hour care and/or invasive ventilation, and/or a child having a continuously unstable condition

A family in receipt of a lower level of nights might be based on factors such as:

- Family carer has support from family and /or the amount of formal care (e.g. Children’s Continuing Care package) outweighs the amount of informal care provided to the child.
- The child whose condition remains largely unchanging, but who may have episodes of acute illness or instability. This may or may not require nursing intervention.

## Appendix C – Appraisal of potential service models

We assessed four potential service models against the principles agreed by the project group.

### Model 1 – Current model i.e. commission a bed-based provision and home-based provision from Sheffield Children’s Hospital

Principle	Delivery
Choice and flexibility	This would not provide any choice for the family or the flexibility in how families access their allocation. The only bed-based/overnight service is from Ryegate House and for home based respite from the Helena Team so this limits choice and flexibility.
Quality and sustainable	The Ryegate House respite unit closes on a Wednesday. There have also been other unplanned closures.  Families have told us that the Helena Nursing service respite offer has also been cancelled on occasions at short notice.
Financially viable	The cost of individual night stays is significantly higher than that of other CCGs and Local Authority provision.  It would also not be viable if all the families estimated to be in scope wanted to access the service.
Based on need	Children under two year olds are not offered bed-based provision.  Ventilated children are not offered bed-based provision.
Transparent assessment and allocation process	Current process would be changed to make assessment and allocation system transparent and fair
Responsive	The service is responsive to emergencies and family needs where possible. However, not all families are aware of this offer. Ryegate House is closed on Wednesdays’ and the Helena Nursing Service offer currently doesn’t provide overnight home provision (care up to 10pm)
Other comments	Travel is largely by school transport (except school holidays) which is valued by families

<b>Conclusion</b>	<p><b>We do not believe this is a viable option as it would not provide the choice and flexibility that families have said they want.</b></p> <p><b>It is also not financially sustainable when taking into account the additional families that are in scope for this care.</b></p>
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**Model 2 – Offer all respite through Personal Health Budgets** - this would mean allocating money to enable a family to purchase their own short-break/respite care or alternative arrangements to meet the needs of their child. This option would mean we would no longer commission a service provision but families would be able to buy support from any providers offering this service if they chose.

<b>Principle</b>	<b>Delivery</b>
Choice and flexibility	Choice and flexibility would only be improved if the market was fully developed.
Quality and sustainable	<p>Organisations and agencies can go through a CCG process of approval to provide this type of care and families can access this list of providers. (Known as Any Qualified Providers).</p> <p>For families who choose a more informal care arrangement (eg a family member or personal assistant) we would first ensure that any personalised plan appropriate.</p> <p>Any provider of NHS bed-based and home-based short breaks is unlikely to provide the service without a guaranteed income. The market for overnight bed-based provision is currently limited and would require further stimulation to support this option.</p>
Financially Viable	As referenced above, this would remove the guaranteed income stream for providers
Based on need	Services would be based around the needs of the family.
Transparent assessment and allocation process	New processes would be introduced to make assessment and allocation system transparent and fair
Responsive	Assurances that cover be available for staff sickness and other emergencies. This may be difficult if parents employ their own

	<p>personal assistants.</p> <p>It may be difficult to provide a responsive service with cover for staff sickness and emergencies where there is no service commissioned by the CCG eg families employing their own support/personal assistants</p>
Other comments	<p>Families highly value having an overnight bed-based provision. Sustaining this provision when there is little alternative is important to families.</p> <p>It is apparent from the engagement that families know very little about PHB. Many families would like to know more and some would like to know about the option of a PHB to provide greater flexibility in how and when they access support.</p> <p>The CCG would have to ensure capacity to administer and monitor arrangements made through PHBs.</p>
<b>Conclusion</b>	<p><b>While in theory this would offer greater flexibility and choice to families, there does not appear to be the market to fully support this approach for the number of families in scope at the moment, although this could develop in response to demand.</b></p>

### **Model 3 – Jointly commissioned bed-based facility with Local Authority**

This would involve moving the bed-based provision from Ryegate House and commissioning a facility jointly with the Council as an alternative.

<b>Principle</b>	<b>Delivery</b>
Choice and flexibility	<p>There may not be the improvement in choice from the existing arrangements. This would take time as much of the provision commissioned by Sheffield City Council cannot accommodate the children in scope of NHS short-breaks.</p>
Quality and sustainable	<p>This would be a change for the existing Ryegate users and transition would have to be carefully managed.</p> <p>Quality would have to be put in place to match Ryegate:</p> <ul style="list-style-type: none"> <li>• Building/equipment</li> </ul>

	<ul style="list-style-type: none"> <li>• Staff skills and group</li> </ul> <p>There would no longer be a problem transitioning between NHS and Local Authority provision when needs change.</p> <p>Commitment and funding from individual partners would be a risk as part of a joint provision. This risk would also be associated with the drive for personalisation and personal budgets.</p>
Financially Viable	Significant investment would be needed to develop a new service and at present there is no further resource available.
Based on need	A needs assessment would determine size and site of the provision.
Transparent assessment and allocation process	New processes would be introduced to make assessment and allocation system transparent and fair
Responsive	The facility could be bigger and able to meet a wider range of children and young people and could therefore be more flexible
Other comments	This would also apply to a single private provider. There are risks attached due to cost pressures in children's provision in SCC and their plans to consider future short-breaks model
<b>Conclusion</b>	<b>Although this could improve flexibility and would support greater integration between health and social care services, this would require significant investment so at the current time this is not a viable model.</b>

#### Model 4 – Mixed model

This would involve commissioning a range of provision including bed-based and home-based and also using personal health budgets.

Principle	Delivery
Choice and flexibility	Greater choice and flexibility (within limits). This would provide families with the overnight bed-based offer that they value and the opportunity to seek flexibility in how and when they access short-break provision.

Quality and sustainable	Organisations and agencies can go through a CCG process of approval to provide this type of care and families can access this list of providers. (Known as Any Qualified Providers).  For families who choose a more informal care arrangement (eg a family member or personal assistant) we would first ensure that any personalised plan appropriate.
Financially Viable	If more people want Personal Health Budgets and choose to use the money in a different way, this would impact on the existing commissioned bed-based and home-based service
Based on need	The new assessment and allocation process will ensure the family circumstances are reflected alongside the needs of the child (eg family support available) As a new model we can ensure need is met based on consultation and needs analysis.
Transparent assessment and allocation process	New processes would be introduced to make assessment and allocation system transparent and fair
Responsive	The level of responsiveness (emergency cover) would vary between the different models in place. This would need to be part of the commissioning process.
Other comments	Families have stated that they value overnight, bed-based provision for a 'proper' short-break'. While home-based provision was not as valued, those who do receive regularly place high value on this. To allow for choice, flexibility and responsiveness a range of provision needs to form part of the offer to families.
<b>Summary</b>	<b>This option gives families the greater level of choice and flexibility that they have indicated they would like. It also provides an opportunity to provide more personalised support to meet families' needs.</b>

Model 4 scored most highly in the appraisal process and will be identified as our preferred model in the consultation