

# Changes to children's NHS funded short breaks

(formally respite)

**NHS Sheffield CCG would  
like to hear your views**

**Public consultation - 14 February - 28 March 2018**

# 1

## Overview

This booklet is about children's NHS short breaks or respite care for children with complex neuro-disability, multiple and profound physical and learning disability and for children with life-limiting conditions and some changes we would like to make as a result of talking to families and health professionals and our partners in social care over the last couple of years.

We want to make sure that NHS funded short breaks services for children with complex health needs are:

- Fair for families
- Easy for families to access
- Flexible for families

## About us

**We are NHS Sheffield Clinical Commissioning Group (CCG)**

### Clinical

We are made up of GPs and other healthcare professionals who know your health needs and how to meet them.

### Commissioning

On your behalf, we plan, buy and monitor the majority of local health services that you need and use, such as those from hospitals and community services.

### Group

We are an NHS organisation working on behalf of 82 Sheffield GP practices, accountable to you, the taxpayer.

**This booklet gives lots more information, but at a glance we would like to hear your views about our plans to:**

### **Introduce a single assessment process**

We are proposing to create a single assessment process for NHS short breaks services that links with Children's Continuing Care and Sheffield City Council's assessment processes for short breaks.

**more on page 8**

### **Introduce a new system for allocating short breaks**

We are proposing to introduce a banding system so that there is a clear and fair approach for allocating short-breaks. This would provide a framework for different levels of care according to the different health needs of each child and the needs of their families or carers.

**more on page 9**

**It is really important that we hear from people who use the service now and who might use the service in the future - let us know your experiences, concerns and ideas. Details on how to contact us are on page 16.**

### **Change the way short breaks are provided in the future**

To make sure families have a more personalised and flexible service, we have looked at a number of different ways we could provide short breaks. These included:

#### **Model 1**

Continuing with the bed-based and home-based services we have now.

#### **Model 2**

Providing all short breaks through Personal Health Budgets.

#### **Model 3**

Developing a new bed-based service with Sheffield City Council.

#### **Model 4**

Offering a mixed model that includes bed & home-based provision & Personal Health Budgets.

We assessed these models against a set of important principles for improving short breaks. As a result we have recommended Model 4 – but we want to hear your views.

**more on page 11**

# 3

## Introduction

This booklet is about some changes we think would improve the short breaks (or respite) services that we commission for children in Sheffield with complex health needs.

When we talk about complex health needs in this document, we generally mean children with complex neuro-disability, multiple and profound physical and learning disability and children with life-limiting conditions.

Short breaks services are a way of giving parents/carers a much needed break from their caring responsibilities and a way of improving outcomes for the children, e.g. to support independence and socialising with other children. We know how important short breaks are to the families using them, and have been reviewing the current services to make sure they are meeting families' needs and will continue to do this in the years ahead.

Over the last 18 months, we have been talking with families who receive this NHS care (please see page 20 for details) and have looked at some changes we think we need to make. We would like to hear your views on these.

This document explains the changes we are proposing to make and why. We want to provide a service that is more flexible and personalised for families and also ensure there is a fair system that supports all families who are eligible for this type of care.

To do this, we need your views. There are lots of ways to find out more and have your say, which are also included on page 16 onwards.

The closing date for comments is 28 March 2018, and no decisions will be made until after we have reviewed all the feedback at the end of the consultation. We look forward to hearing from you.



**Mandy Philbin**  
**Acting Chief Nurse, NHS Sheffield CCG**

# Short Break Services

## About Short Breaks

Short breaks (or respite care) are provided to families with children who have complex health needs and who care for them around the clock. Respite care gives the parents or carers the opportunity to take a break from caring for their child while trained support staff provide help. This can be with the day-to-day looking after of their children, either in their own home or in specially equipped respite facilities. Short breaks can range from a few hours in the home to longer stays away from the family home in a special unit.

There are different types of short breaks services available to families with children who have disabilities in Sheffield. These are provided by different organisations, including Sheffield City Council and Sheffield Children's Hospital NHS Foundation Trust.

This consultation document is focusing on the **NHS funded** short breaks provided for families and carers of children with complex health needs.

NHS Sheffield CCG currently commissions, or buys, two types of short break services for children with complex health needs:



### Ryegate House Respite Unit

Ryegate House is a six-bed unit available for children aged from two to 19 with complex neurological conditions. The service is run by Sheffield Children's Hospital NHS Foundation Trust. Children and families access the service through referral from a range of health professionals and schools to the respite unit. An assessment tool is used to check whether children are eligible to access the service and what level of need (medium or high) they have. This is repeated annually.



### Helena Nursing Service

The Helena Nursing Service is also run by Sheffield Children's Hospital and provides a short-break service in the parents or carers home. This is for families of children with complex health needs that are under the care of a neurologist. Children and families access the service through referral from a health professional direct to the team. The team completes an assessment to determine the support required.

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# The need to change

## Why do we need to make some changes?

Part of our role as a CCG is to make sure that the services we commission meet the needs of people using them and offer the best value for public money. We regularly review all services to make sure we achieve this.

We have identified a number of areas where we think we need to make changes to improve short-break services, and to ensure we can continue to meet the needs of children with complex health needs and their families.

**Find out more about what families told us in Appendix 1 (page 20).**

## Fairness

At the time of writing, there are 30 children accessing the Ryegate House Respite Unit, and 34 children who had applied and were eligible for the Helena Nursing Team service (although not all were accessing the service).

However, an assessment of children receiving regular care at Sheffield Children's Hospital has shown that there are **an estimated additional 30-50 children who could be eligible** for NHS-funded short breaks either now or in the near future.

Currently there is **not a consistent approach** to allocating short breaks so some people get more than others even though they may have the same needs.

Also, some families who are entitled to short breaks services are not accessing any services at all at the moment. We want to make sure everyone who needs it can get this valuable support.

As we estimate there could be up to 50 families who would be eligible for support now or in the near future, we need to think about how to meet their needs.

We also know that **Black and Minority Ethnic (BME) communities are generally underrepresented** in services for disabled children, and this could signal that there are more people whose needs are not being met by the current services.

## Making it easier to access

At the moment there are separate processes for Ryegate Respite Unit, Helena Nursing Team, Continuing Healthcare and Sheffield City Council services. This means families often have to go through multiple assessments, which take up valuable time for them.

Families have told us that they would prefer **a more streamlined assessment and review process** so we want to look at a new approach to make it as easy as possible for people to access short break services.

Having a joined up process also means that families are provided with the best possible package of care, taking into consideration **what is available from all health and social care providers** (e.g. The NHS, local authority and voluntary sector).

## Flexibility

Families have told us that they would like more flexibility and choice, so we want to offer **a more personal approach** and make sure families can get the type of support that they feel will best meet their needs.

One way of doing this is to encourage **more use of Personal Health Budgets**, which allow people to use the money allocated to them in the way that will best meet their needs (see below for more details).

This might also help people who would benefit from support but aren't currently using the services, as it would make more options available to them.

### What is a Personal Health Budget?

A personal health budget is an amount of money allocated to an account for you to use to **support your health and wellbeing needs**. It is planned and agreed between you (or someone who represents you), and your local NHS team.

It is not new money, but a different way of spending health funding to meet your individual needs and give you more choice and control over how this is done. A personal health budget allows you to manage your healthcare and support.

More information can be found on page 14.

## Making it financially sound

We have to provide a service that the city can afford, making sure we get the best value for public money, and, that we can continue to provide NHS short breaks to all the families and carers who need them in the years ahead.

While the numbers of children using the current services have stayed pretty much the same, we know that the population is slowly increasing and we need to prepare for this. We also know that there are people who are eligible for short break services who are not using them at the moment, so we need to think about how we can best use resources to support them as well.

## Other important factors

Any child who stays away from their home for more than 75 days a year is considered in law as a 'Looked After Child'. **This does not mean that your child will be removed from your care.** It does mean that you should have a designated social worker to regularly review family circumstance and your child's needs.

- Under the Children's Act 1989, a child staying away from the home for more than 75 days can be considered a 'Looked After Child' or a child 'in care'.
- In Sheffield, the maximum allocation for NHS short breaks away from home exceeds this, so as a result some children could become 'Looked After' in the eyes of the law when attending the short breaks service.
- National best practice is therefore that children and families should only receive over 75 days of care in exceptional or emergency circumstances.

It is important that this is considered and families are informed about this when receiving short breaks services. The packages currently offered at Ryegate House Respite Unit exceed 75 days. While some families may need this, **it is important that the routine offer of short breaks services works within the 75-day threshold.** So we need to look at changing the number of nights offered.

For more information, please search for 'Looked After Children' on the Gov.uk website.

# Proposed changes

**To address these issues, we are proposing to make the following three changes:**

## 1. Introduce a single assessment process for families

We are proposing to create a single assessment process for **NHS short breaks services**, which will link with Children's Continuing Care and the Sheffield City Council's assessment processes for short breaks.

### Why we are suggesting this

- This will be better for families and children as it will ensure that services are properly linked and that care packages are flexible.
- It will reduce the number of assessments for children accessing services through the Council and the NHS.
- It also supports closer working between health and social care in the city, which all the organisations involved are committed to as a new way of working in the years ahead.

### How this would work

It would be a joined-up process between Sheffield health and social care to ensure that family circumstances are reflected, in addition to the child's health needs. The assessment results will help us ensure families receive the short break support they need.

After the initial assessment, there would be a review after three months to ensure that care is meeting the needs of the child. Reviews would then take place every year unless a family's circumstances have changed.

The support available to families would also include a 48 hour emergency stay to help in emergency circumstances, such as the hospitalisation of the parent/carer or a sibling.

## 2. Introduce a new system for allocating short breaks

We are proposing to introduce a banding system so that there is a clear and fair approach for allocating short breaks. This would provide a guidance framework for different levels of care according to the different health needs of each child and the needs of their families or carers.

### Why we are suggesting this

- We believe that the current system could be fairer. We want to provide a clear and consistent approach for children and families accessing short breaks.
- We want to make sure that children and families get the right support to meet their needs.
- This would work within the 75-day threshold for 'Looked After Child' status and bring us into line with other areas nationally (see page 7 for details).

### How this would work

Allocations will take into account both the level of care needed to support the child's health needs and family circumstances, including family arrangements and the health needs of main carers and siblings.

The number of nights of residential breaks would be allocated based on each family's needs, using a banding system. We are working with Sheffield Children's Hospital and Sheffield City Council to develop a guideline. As a starting point, we have looked at other areas and have developed the outline below as an example of how it could look in very simple terms.

We would need to define exactly what each level in real terms means, review the number of nights for each level, and make sure they provide the support needed. We would like your views on this.

**please see table on the next page**

**Level of need** – which is based on the assessment process mentioned earlier, which looks at family circumstances as well as the child’s health needs

**Example of number of nights \***

**Level A:** Lower need for overnight short break away from the family home

**Up to 16 nights a year**

**Level B:** Medium need for short break care

**17 - 28 nights a year**

**Level C:** Higher need for short break care

**29 - 35 nights a year**

**Level D:** Very high need for short break care

**36 - 49 nights a year**

**Level E:** Exceptional need or emergency circumstances

**50 + nights a year**

\* 'Nights' allocation is a resource (or budget) that could be used in different ways, e.g. clubs.

As mentioned earlier, the assessment process is personalised and would look at the family circumstances and the individual child’s needs. To give you an example, a lower need for short breaks could apply to a family that has lots of support and where the condition of the child is generally stable. A higher level of need could be a child with a continuously unstable condition that requires lots of support but the family has little or no network to help them with this (e.g. a single parent).

Generally, families who need the most short break support for their child include single parents, parents who may have their own physical and/or mental health conditions, another child with disabilities or where there are child protection concerns. For many families, this new system would not mean any reduction in the amount of nights they receive. On average, families used 49.5 nights in 2016/17 and figures for the first part of this financial year suggest an average of 46 nights.

We will work with families to agree a package of support that best meets their needs and look at alternative support for any families who have been accessing more than 75 nights. Packages would be reviewed every year as part of your annual review, or in the event of any changes in your circumstances.

### 3. Change the way short-breaks are provided in the future

To make sure families have a more personalised and flexible service, we have looked at a number of different ways we could provide short breaks. These included:

#### Model 1

**Continuing with the bed-based and home-based services we have now**

#### Model 2

**All short breaks provided through Personal Health Budgets**

#### Model 3

**Developing a new bed-based service with Sheffield City Council**

#### Model 4 (preferred by the CCG)

**A mixed model: a range including bed and home-based provision and Personal Health Budgets**

Full details are available in Appendices 2 and 3 - in summary, Models 1 and 3 were not considered to be viable at this time by members of the NHS Sheffield CCG, Sheffield City Council, Sheffield Children's Hospital NHS Foundation Trust, and the Sheffield Parent Carer Forum.

Model 4 scored most highly with a set of important principles (see Appendix 2) for improving short breaks (information on this is on the next page). **Because of this Model 4 is the approach we are recommending, but we want your views.**

# Our preference

## More about Model 4: our recommended approach

Following parent's feedback in 2016/17, we established a project group who have assessed each Model against a set of important principles for improving short breaks (please see Appendices 2 & 3). These principles are:

- Ensuring patient choice and voice
- A quality provision which can be maintained (is sustainable)
- Based on need and balanced across the user group
- A clear and transparent assessment process
- A responsive service which can support families in emergencies and where additional support is required
- A service which is affordable and financially viable

Model 4 scored most highly on these principles. Adopting Model 4 would mean we would continue to commission both bed-based and home-based short-break services, and offer families a package of care to meet their needs. We would also use personal health budgets to offer greater choice and flexibility to families so they could choose different types of support if they felt these would be more appropriate for their needs.

### Why we are suggesting this

- It gives a greater level of choice and flexibility that families have said they would like
- It would offer a range of provision, helping to ensure we can meet the different needs of all families.
- It provides an opportunity to give more personalised support to meet families' needs.
- It would offer more options for supporting families in emergency situations

### How this would work

Families would continue to receive an allocation using the new system outlined as outlined on page 10. This would comprise an appropriate mix of services to meet your specific needs and could also include the use of personal health budgets to allow you greater choice over the type of support that you receive if you want it. This would allow you to choose a different respite service if you felt it was more suited to your child's needs, as in the example overleaf. There is still a formal process to be followed for the allocation of Personal Health Budgets.

## Example of how Model 4 would work

John lives at home with his parents and twin sister. He is disabled and has multiple healthcare needs. He goes to an overnight bed-based unit occasionally at weekends. It's a great service for the family but the nights are not always flexible. So his mum was keen to find something else for John to be with other children and to enjoy new experiences.

His mum is really keen for John to attend a sensory play session at a specialist children's centre in his home town. Part of the money allocated for John's short breaks services is used to finance sessions at the centre and for a personal assistant to attend with him so his mum could spend time on the school run with John's sister.

John's mother said: "It's allowed us to think really differently about what we want for John and about short breaks. It has given us real flexibility as a family and new experiences for John."

## Alternative option: Model 2

Of the other models we assessed, the other possible option would be to move to **providing all short breaks through personal health budgets**. This would mean that the CCG stopped commissioning specific services and families would be able to use their budget to fund support from any available service that met their needs.

The potential problem with this is that existing services would not have a guaranteed income stream as they do now so **could be put at risk**. However, it might also mean that other local services were developed in response to the demand from families in Sheffield. Currently there are very few local providers for children's overnight short breaks away from the family home.

# More information

## More about Personal Health Budgets

Personal budgets allow a move away from previous 'one-size fits all' models of care and support and give individuals, and their families, choice and control over the support they receive. **They do not give people any additional money but allow them to use the money allocated to them in the way they think best meets their needs.**

Short breaks are a fundamental part of any support package a child or young person receives. Not only do they give carers a break from caring, they allow young people to meet friends, take part in activities, develop independence and have fun. You can use a personal health budget to pay for a wide range of items and services, including therapies, personal care and equipment.

You don't have to change any healthcare or support that is working well for you just because you get a personal health budget, but if something isn't working, you can change it.

A Personal Health Budget is about using the allocated budget (not new money) used for NHS short-breaks differently, to improve outcomes for the child and family.

In this situation, it would mean that the **families could choose to spend the equivalent cost of the respite care they receive on alternative options** instead of being restricted to the two services currently offered.

For example, people who are already receiving personal health budgets have chosen to use the money in different ways to the traditional services, including:

- Time away as a family – you could take someone on holiday with you to provide support while you are away or perhaps find some respite provision at your holiday destination
- Music clubs and swimming lessons, brownies and cubs or support with any activities your child enjoys
- Support with household tasks to free up more time for you to enjoy with your child
- A personal assistant employed to help you as a family.

# Glossary

## Commissioning

At its simplest, commissioning is the process of planning, agreeing, buying and then monitoring services.

## Children's Continuing Care

Children's Continuing Care is the holistic assessment for bespoke packages for children and young people whose needs cannot be met by existing universal and specialist services. These needs generally arise from congenital conditions, long-term deteriorating conditions, accidents or the after effects of serious illness or injury.

## Education Health and Care (EHC) Plans

An EHC Plan looks at all the needs of a child and brings together education, health and care to achieve agreed outcomes. The focus is on what is important to the child or young person – what they want to achieve now and in the future. EHC Plans are available from birth to 25 years. An assessment of the child or young person is carried out before deciding whether they need a plan in place.

## Personal Health Budgets

A personal health budget is an amount of money to support the identified healthcare and wellbeing needs of an individual. [Read more on page 14.](#)

## Primary Care

Care provided by GP practices, dental practices, community pharmacies and high street optometrists. It is many people's first (primary) point of contact with the NHS. Around 90% of patient interaction is with primary care services.

## Secondary Care

Hospital or specialist care that a patient is referred to by their GP or other primary care provider.

## Short Breaks (Respite Care)

Short breaks, or respite care, are provided to families with children who have complex health needs and who care for them around the clock. Respite care gives the parents or carers the opportunity to take a break from caring for their child while trained support staff help.

# Have your say

## Complete the survey

Complete the feedback form online at [www.sheffieldccg.nhs.uk](http://www.sheffieldccg.nhs.uk), or

Complete the feedback form enclosed, tear out and post it back to us for free. Just write (in capitals) FREEPOST NHS SHEFFIELD CCG on the envelope. No stamp required.

## Visit us at a drop in

Come and speak to us at The Circle, 33 Rockingham Ln, Sheffield S1 4FW, on Thursday March 15 anytime between 1:30 - 4:30pm.

## Contact us

Call the Children's Commissioning Team on 0114 305 1028 and we will get someone to call you back.

Alternatively, email [SHECCG.ChildrensCommissioning@nhs.net](mailto:SHECCG.ChildrensCommissioning@nhs.net)

## Deadline

You have until 28 March 2018 to provide your feedback.

This will help us decide which option is best for Sheffield, and we will keep you informed of our decisions after this deadline has passed.

**If you need this leaflet in a different language, audio, large print or braille, please email us at [sheccg.comms@nhs.net](mailto:sheccg.comms@nhs.net) or call 0114 305 1088.**

# Feedback form

Please give us your feedback by completing this short survey:

1. What do you think about the reasons we've given for why we need to make changes? [\(information on page 5\)](#)

2. Do you think having a single assessment process for [NHS short breaks services](#) will make it simpler for you to get the support you need? [\(information on page 8\)](#)

- Yes
- No
- Not sure

Please tell us why:

3. Are there any particular factors you think we should take into account if we develop a joined-up process with Children's Continuing Care and Sheffield City Council for short breaks? [\(information on page 8\)](#)

4. Do you think introducing an allocation banding guideline for allocating short breaks would help make this clearer and fairer for all families? [\(information on pages 9 & 10\)](#)

- Yes
- No
- Not sure

Please tell us why:

5. What do you think about the proposed banding system we have suggested [\(page 10\)](#)? Are there any changes you feel should be made to the proposed banding system on [page 10](#) if we adopt this approach for allocating short breaks?

**Once completed**, please tear both pages out and post it back to us for free. Just write (in capitals) FREEPOST NHS SHEFFIELD CCG on the envelope. No stamp required.

Alternatively, you can fill this form out online at [www.sheffieldccg.nhs.uk](http://www.sheffieldccg.nhs.uk)

**6. Do you think the recommended service model will give families more choice and flexibility? (information on page 12)**

- Yes
- No
- Not sure

Please tell us why:

**7. Do you think one of the alternate models we looked at would be better than the one we have recommended? (information on page 11)**

- Yes
- No
- Not sure

Please tell us why:

**8. Is there anything about the proposals that you feel would have a more positive or negative effect on you, and if so why?**

**9. We are really keen to hear what you think about our proposals and how they will affect you so please use the space below for any other comments, concerns or ideas about the changes being proposed you may have:**

**10. Please tell us if you are:**

- A member of the public
- Someone who works in primary care
- Someone who works in secondary care
- Someone who works in social care.
- Receiving respite care for your child from Sheffield City Council
- Currently using NHS short breaks (respite) for your child: please tell us which service(s) you're currently using:

**Equality Monitoring - OPTIONAL****Where did you hear about this consultation?**

Local newspaper		Twitter/Facebook		Leaflet in public venue	
Website		Public meeting		Word of mouth	
Email		Other:	Please specify		

This information will be kept confidential and you do not have to answer all of these questions, but we would be very grateful if you would.

**Please tell us the first part of your postcode (e.g. S9, S35)**

Please enter here	Prefer not to say
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**What is your gender?**

Female		Male		Prefer not to say	
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**Transgender**

Is your gender identity different to the sex you were assumed to be at birth?

Yes		No		Prefer not to say	
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**What is your age?**

years	Prefer not to say
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**What is your sexual orientation?**

Bisexual (both sexes)		Lesbian (same sex)		Gay man (same sex)		Heterosexual/ Straight (opposite sex)	
Other:	Please specify				Prefer not to say		

**What is your ethnic background?**

Asian, or Asian British		Black, or Black British		Mixed / multiple ethnic group		White		Other	
Chinese		African		Asian & White		British		Arab	
Indian		Caribbean		Black African & White		Gypsy/Traveller			
Pakistani				Black Caribbean & White		Irish			
Other Asian background		Other Black background		Other Mixed / multiple ethnic background		Other White background			
Prefer not to say				Other:		Please specify any other ethnic group here			

**Do you consider yourself to belong to any religion?**

Buddhism		Christianity		Hinduism	
Islam		Judaism		Sikhism	
No religion		Prefer not to say		Other:	Please specify

**Do you consider yourself to be disabled?**

The Equality Act 2010 states that a person has a disability if: 'a person has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on that their ability to carry out normal day-to-day activities'

Yes		No		Prefer not to say	
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**If yes above, what type of disability do you have? (Tick all that apply)**

Learning disability/difficulty		Long-standing illness or health condition		Mental Health condition	
Physical or mobility		Hearing		Visual	
Prefer not to say		Other:	Please specify		

**Do you provide care for someone?**

Such as family, friends, neighbours or others who are ill, disabled or who need support because they are older.

Yes		No		Prefer not to say	
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# Appendix 1

## Engagement Overview – what families have told us

We started the review by setting up a group involving staff from the CCG, Sheffield City Council, the Helena Nursing Team, Ryegate Respite Unit and the Parent Carer Forum.

During February 2016, we carried out telephone interviews with a number of families using the services to get their feedback on them. Between August and November 2017 we contacted all 54 families who were then accessing the services provided by Ryegate Respite Unit and the Helena Nursing Team and invited them to take part in an engagement event or telephone interview to share their views on the services.

### Key areas that families and carers considered to be very important:

- Families think it is very important that NHS short breaks provision is away from the home in a bed-based facility
- Access to emergency nights is very important
- Families think that a reduction in nights would impact on their ability to care for their child and see this as very important
- Flexibility in choosing nights is very important.

### Themes from the engagement in February 2016:

- Parents place great value on the relationship with staff at Ryegate Respite Unit and have confidence in them
- Some families liked the routine and structured element to the package they receive and the one-week holiday was valued by all
- Some bed-based provision (for overnight stays) was very important
- Families considered they received a flexible service from Ryegate but some highlighted the disruption caused by the summer closure in 2015
- There were strong views that the service should be NHS provided and nurse-led
- Concerns were raised about cutting services and the quality of private sector companies that might wish to provide the service.

# Appendix 1

## Engagement Overview – what families have told us

### Other themes from our most recent conversations with families and carers:

- Most families would prefer a more streamlined assessment process and one that is linked with other packages of care available
- Ryegate Respite Unit and the relationships with staff is valued and some commented that their children look forward to staying there
- Most families felt that a reduction in the allocation of nights at the unit would impact on their ability to care for their child – but some said more flexibility in when they can access short breaks might ease the impact of a reduction
- Most families said the thing they would change is being able to choose when and how they access nights
- Some families find single night stays difficult
- The one-week holiday is valued by those who receive it
- Some families raised the disruption caused when the unit closed for a night in August 2017 and a three-month closure in summer 2015.
- Most families could not recall having an annual assessment since they started using Ryegate Respite Unit
- Families who have had a consistent home respite service from the Helena Nursing Team value this service highly. Others who have had inconsistent care or cancellations do not value it
- Families have often not heard of Personal Health Budgets, or if they have there is little or no understanding of them.

# Appendix 2

## Development of proposals and appraisal of potential service models

We established a project group, made up of key partners from NHS Sheffield CCG, Sheffield City Council, Sheffield Parent Carer Forum and Sheffield Children's Hospital NHS Foundation Trust. The group oversaw the development of the proposals to improve short break services. A set of principles, taking into account the feedback from family conversations (see Appendix 1) were agreed to assess potential proposals against:

### These are:

- Ensure patient choice and voice
- Quality provision which can be maintained (is sustainable)
- Based on need and balanced across the user group
- A clear and transparent assessment process
- A responsive service which can support families in emergencies and where additional support is required
- A service which is affordable and financially viable

**We looked at four potential service models and assessed them using these principles, the results of which are in Appendix 3.**

# Appendix 3

## Appraisal of potential service models

We assessed four potential service models (see page 11) against the principles agreed by the project group (see Appendix 2).

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

#### Choice & flexibility

This would not provide any choice for the family or any flexibility in how families access their allocation. The only bed-based/overnight service is from Ryegate House and the home-based respite is from the Helena Team so this limits choice and flexibility.

#### Quality & 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 & allocation process

The current process would be still changed to make the assessment and allocation system transparent and fair.

# Appendix 3

## Appraisal of potential service models

### Model 1 continued

#### 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 routinely provided up to 10pm)

#### Other comments

Travel is largely by school transport (except school holidays), which is valued by families.

## Conclusion: Model 1

**We do not believe this is a viable option, as it would not provide the choice and flexibility that families have said they want.**

**It is also not financially sustainable when taking into account the additional families that are in scope for this care.**

# Appendix 3

## Appraisal of potential service models

**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.

### Choice & flexibility

Choice and flexibility would only be improved if the market was fully developed.

### Quality & 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 (this is known as 'Any Qualified Providers'). For families who choose a more informal care arrangement (e.g. a family member or personal assistant), we would first ensure that any personalised plan is appropriate.

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.

### 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 & allocation process

New processes would be introduced to make the assessment and allocation system transparent and fair.

# Appendix 3

## Appraisal of potential service models

Model 2 continued

### Responsive

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, e.g. families employing their own support/personal assistants.

### Other comments

Families highly value having an overnight bed-based provision. Sustaining this provision when there is little alternative is important to families.

It is apparent from the engagement that families know very little about Personal Health Budgets. Many families would like to know more and some would like to know about the option of a Personal Health Budget to provide greater flexibility in how and when they access support.

The CCG would have to ensure capacity to administer and monitor arrangements made through Personal Health Budgets.

## Conclusion: Model 2

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.

# Appendix 3

## Appraisal of potential service models

**Model 3 – Jointly commissioned bed-based facilities with Local Authority** - this would involve moving the bed-based provision from Ryegate House and commissioning a facility jointly with Sheffield City Council as an alternative.

### Choice & flexibility

There may not be an 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.

### Quality & sustainable

This would be a change for the existing Ryegate users and the transition would have to be carefully managed.

Quality would have to be put in place to match Ryegate:

- Building/equipment
- Staff skills and group

There would no longer be a problem transitioning between NHS and Local Authority provision when needs change. Commitment and funding from individual partners would be a risk as part of a joint provision. This risk would also be associated with the request for personalisation and personal budgets.

### 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 & allocation process

New processes would be introduced to make the assessment and allocation system transparent and fair.

# Appendix 3

## Appraisal of potential service models

Model 3 continued

### Responsive

The facility could be bigger and able to meet a wider range of children & young people. This 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 Sheffield City Council, and their plans to consider future short breaks model.

## Conclusion: Model 3

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.

# Appendix 3

## Appraisal of potential service models

**Model 4 – mixed model** - this would involve commissioning a range of provision (including bed-based and home-based), and also using personal health budgets.

### Choice & 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 & 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 (this is known as 'Any Qualified Providers').

For families who choose a more informal care arrangement (e.g. state a family employing a 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 (e.g. making sure family support is available). As a new model, we can ensure need is met based on consultation and needs analysis.

### Transparent assessment & allocation process

New processes would be introduced to make the assessment and allocation system transparent and fair.

# Appendix 3

## Appraisal of potential service models

### Model 4 continued

#### Responsive

The level of responsiveness (emergency cover) would vary between the different models in place. This would need to be considered as 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 it regularly place a high value on this. To allow for choice, flexibility and responsiveness, a range of provision needs to form part of the offer to families.

## Conclusion: Model 4

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.

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

## **If you have any further questions, big or small, about this consultation:**

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