

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

Governing Body meeting

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24 May 2018

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Purpose of Paper	
<p>To provide the Governing Body with the findings following the public consultation to progress service change for a new assessment process, resource allocation system, and service model for Children’s NHS Short-breaks provision in Sheffield.</p> <p>Due to the size of the supporting appendices, these are included in the information pack that has been emailed to members separately.</p>	
Key Issues	
<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 (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 reflects;</p> <ul style="list-style-type: none"> • An outdated service model of short-breaks/respite • An inequity of provision (some families receiving high packages of care while others get nothing) • A drive for greater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 • Drive for personalised health planning and Personal Health Budgets • Greater integration between health and social care • Financial context and the need to ensure value for money <p>Following review, pre-consultation engagement and public consultation, 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>	
Is your report for Approval / Consideration / Noting	
For consideration and approval	

Recommendations / Action Required by Governing Body

The Governing Body is asked to:

- Consider whether the Public Consultation undertaken has provided enough opportunity and time for the public to feedback, and whether the feedback is enough to progress service change.
- Consider the findings and key themes from the public consultation and the proposed future service offer.
- Consider the recommendations and next steps to develop and implement the three elements of service change:
 - a single, joined-up (with Children’s Continuing Care and Sheffield City Council short breaks) assessment process
 - the introduction of a resource allocation system
 - the mobilisation of a mixed model of service provision that includes overnight home- and bed-based provision and Personal Health Budgets.
- Approved the recommendation to progress service change

Governing Body Assurance Framework

Which of the CCG’s objectives does this paper support?
To ensure there is a sustainable, affordable healthcare system in Sheffield

Are there any Resource Implications (including Financial, Staffing etc)?

Management and clinical time to complete the implementation of the project and required service change.

Have you carried out an Equality Impact Assessment and is it attached?

Yes (see Appendix A)

Have you involved patients, carers and the public in the preparation of the report?

Families and the public have been involved as part of the Public Consultation (undertaken February-March 2018). Pre-consultation engagement has also been undertaken with families (August – November 2017). This is in addition to engagement work undertaken as part of the initial service review in February 2016. All this feedback has been looked at collectively to shape the proposals for service change.

Sheffield Parent Carer Forum also attend the Children’s NHS funded short breaks project steering group to provide a parent voice throughout the planning, developing and mobilising of service changes.

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1. Introduction / Background

1.1 On 15 February 2018 the Children's NHS funded short breaks consultation was launched by Sheffield Clinical Commissioning Group (SCCG). The consultation ran for six weeks and closed on 28 March 2018. This consultation followed detailed engagement work with families currently accessing service provision and approval at SCCG Governing Body on 11 January 2018.

1.2 The services under review are provided by Sheffield Children's NHS Foundation Trust (SCFT) that deliver home based short breaks (Helena Nursing Team) and an overnight bed-based respite unit (Ryegate House Respite Unit). Approximately 118 children are thought to be in scope of NHS funded short breaks. At this time services provide care for children and young people with complex neuro-disability, multiple and profound physical and learning disability and for children with life limiting conditions. There are currently 54 children accessing service provision from either or both services.

1.3 The case for change for reviewing NHS funded short breaks provision is based on:

- An outdated model of short-breaks/respite
- Inequity of provision (some families getting the lions share while other get nothing)
- The 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
- The need to ensure that service provision is equitable, sustainable, personalised and allows greater choice and control for children and families.

1.4 The Governing Body is asked to:

- Consider whether the Public Consultation undertaken has provided enough opportunity and time for the public to feedback, and whether the feedback is enough to progress service change
- Consider the findings and key themes from the public consultation and how these will shape the future service offer
- Consider the recommendations and next steps to develop and implement the three elements of service change:
 - A single, joined-up (with Children's Continuing Care and Sheffield City Council short breaks) assessment process
 - The introduction of a resource allocation system
 - The mobilisation of a mixed model of service provision that includes overnight home- and bed-based provision and Personal Health Budgets.
- Approve the recommendation to progress service change.

2. The Consultation Proposal

2.1 There are three parts to service change that were proposed and outlined to families in the NHS funded short breaks consultation:

1. The introduction of a single assessment process for NHS funded short breaks that are linked to Children's Continuing Care and Sheffield City Councils processes for short breaks to avoid duplication and ensure the health and social care needs of the child and family are fully considered.
2. The introduction of a banding system for allocating NHS funded short breaks to ensure fairness
3. The proposal of a new service model and a change to the way short breaks are provided. Four proposed models were outlined with the consultation document with the preferred option identified – model Option 4 a mixed model including overnight bed and home-based provision and Personal Health Budgets.

2.2 The consultation document (see Appendix B) was shared with key stakeholders for comments prior to launch. Positive feedback was received from Sheffield Parent Carer Forum that the consultation document was well written and that it read as a proposal where no prior decisions had been made. A staff briefing was also developed (initially for SCFT staff) with the aim of providing a background and a summary of the consultation to support conversations with families.

3. Circulation and distribution of the consultation documentation

3.1 The consultation went live on the SCCG website on 15 February 2018 with supporting information and an online survey. The consultation document, staff briefing, web page links and the online survey monkey link were circulated to all families in scope of the service, key stakeholders and partners. A distribution plan developed prior to launch of the consultation was followed to ensure that vulnerable groups and other underrepresented groups were informed and had the opportunity to provide feedback.

3.2 One planned consultation event took place on 15 March 2018 at The Circle venue, Sheffield. Only one parent attended the event that is currently accessing services from Ryegate House Respite Unit.

3.3 Further targeted promotion of the consultation was also undertaken in response to feedback from families and other stakeholders including:

- Telephone contact with 18 families currently in service to offer support to complete the consultation survey
- Additional support and information provided to Sheffield Specialist Schools to promote and encourage families and staff to take part
- Posters and consultation packs were taken to clinics within the hospital and the High Dependency Unit (following feedback from families)
- Consultation circulation via the Sheffield Children's Disability Register
- SCCG Children's Continuing Care and Adult Continuing Health Care Teams were fully briefed on the consultation and provided with packs for distribution.

4. Consultation Feedback - *Who took part?*

4.1. Seventeen people responded to the consultation survey. One parent attended the consultation drop-in session, this parent also completed and submitted a consultation

survey. A further parent provided feedback over the phone. In total 18 people have provided feedback to the public consultation.

4.2 Of the 18 people who took part, eight were parents/carers of children currently using NHS funded short breaks services and a further two were receiving short-break care from Sheffield City Council (SCC). The remaining were members of the public (three) and those who worked in primary (two) and secondary care (two).

4.3 This response rate could be considered low however, it is important to be mindful of the number currently accessing NHS funded short-breaks services (currently 54 children). While there are thought to be approximately 118 children in scope of services (through information provided by SCFT), it is considered that a proportion of these children may be able to access Sheffield City Council short-breaks services and would not require nurse-led short-break care. SCCG, SCFT and SCC are working together to look at numbers and gaps in provision using consultation feedback to drive this.

4.4 It is also important to note that some families (three) when contacted by phone to offer further support commented that they had already had *their* say following the engagement work undertaken in 2017. Sheffield Carers Centre also commented that they were not surprised that families felt they had already contributed given that the engagement telephone interviews were thorough and very much mirrored the consultation information (albeit the consultation provided more detail).

4.5 The demographic information collected identified that respondents were largely female (11, 78%). It is important to identify that no respondents identified themselves as from Black and Ethnic Minority (BME) groups, despite additional efforts to reach these families and to provide support to complete the survey. Both nationally and locally BME communities are considered to be underrepresented in children's disability services.

5. Consultation Summary Feedback - *What the public have told us*

5.1 Respondents were asked questions about the three parts to proposed service changes (outlined in 2.1). The key findings include:

- Eight respondents felt that a single assessment would be more straightforward and simpler. A further seven respondents were unsure whether a single assessment would make things simpler due to concerns that a joint assessment process could create further barriers including delays in receiving care and the ability for services to be responsive under joined up arrangements in emergencies.
- All respondents (18) agree that a banding (resource) system would create a fair and clear allocation process. However, whilst agreeing to this, families were concerned if they received a reduced care package.
- Over half of respondents (10) considered that the preferred model option (option 4 in the consultation document) was the better option of those identified in the consultation (of the four models presented in the consultation). This was reported to offer greater flexibility to families but the extent of choice was questioned by respondents (limited market of short-breaks provision for children with complex health needs) and the impact of demand with of the increased numbers needing to access
- The majority of respondents raised concerns about the impact of a reduced allocation on their ability to care
- Concerns were raised over the management of Personal Health Budgets.

The findings (both quantitative and qualitative) and summary overview can be found in Appendix C, D and E respectively.

6. Review of all findings - themes

6.1 The findings of the public consultation (and the pre-consultation engagement) have been fully reviewed by the Children's NHS Funded Short Breaks Steering Group held on 27 April 2018. This group is made up of members of members from the SC (NHS) FT including a Consultant Paediatric Neurologist and an Associate Director, a member of Sheffield Parent Carer Forum, Local Authority short-breaks and Social Care representatives, Children's Continuing Care, the adult CHC Project Manager and a SCCG clinical lead. This group has supported the review of the engagement findings; developed the principles for the proposed future service model; and supported the development of service options for consultation.

6.2 Key themes were explored and amended by the steering group and approved by the group. The themes were drawn from the pre-consultation engagement and public consultation feedback and include that:

- There is a preference (particularly among families) for a more streamlined, joined-up and coordinated assessment process (as long as this doesn't cause unnecessary delays in receiving care)
- There is a clear agreement that a banding system would create a fairer and clearer allocation process for NHS funded short breaks
- Most families feel that a reduced allocation (e.g. night stays) would impact on their ability to care for their child(ren)
- Families' have a preference for NHS short-breaks provision is away from the home – 'for a proper short-break' e.g. overnight bed-based provision
- Flexibility in how families' choose their nights is also considered is very important to families
- There is a consensus that the preferred mixed service model of overnight home-, bed-based and Personal Health Budgets) is the better (future) service model than those outlined
- Families require a consistent and reliable service (this was in reference to recent night closures at Ryegate House Respite Unit and inconsistent home-based short breaks that is often cancelled as reported by families)
- Access to emergency nights is considered very important to families
- There is a limited understanding about Personal Health Budgets and this is hindered by complexity of options for Personal Health Budgets. However, families have stated that they would not want to manage a Personal Health Budget on top of their caring responsibilities.

7. How will all the feedback from families (and the public) be used to progress service changes?

7.1 The table below reflects the themes of what families and the public have told us and how this will shape the future service.

What service users have told us (engagement February 2016 and August-November 2017 and public consultation February - March 2018)	How this is reflected in our plans for shaping NHS Short-breaks from 1 September 2018
<p>A streamlined and joined-up assessment process that makes the process simpler, avoids duplication and improves communication (between health and social care).</p> <p>It is important that any change in process doesn't cause unnecessary delays in care being received</p>	<p>The assessment and process will be developed with the Children's Continuing Care Process and will be linked to Local Authority short-breaks processes (including social care). The process will ensure that information is coordinated between health, social care and other short breaks providers including Bluebell Wood Hospice. NHS funded short breaks will work to the Children's Continuing Care timescales of 6 weeks from referral to service allocation.</p>
<p>Fairness and transparency of service offer including the published criteria for eligibility for NHS funded short-breaks and a resource allocation (banding) guideline.</p>	<p>Transparent eligibility criteria and resource allocation processes are a priority for the service in future.</p>
<p>Reducing the allocation of NHS short-breaks would impact on families ability to care</p>	<p>Sheffield CCG needs to ensure that provision is financially viable and sustainable for all children that require a service now and in future. The assessment and allocation processes will change in future to ensure equity in access and this will mean that some families could be offered more and some could be offered less. However, families will be supported should their offer reduce and this will be managed over a period of time (to be negotiated with the family). Any change will also be coordinated across services (health and social care) to ensure that any changes in care provision are considered holistically. Personalised planning should ensure that families receive the support they need to care for their child while managing the needs of their family.</p>
<p>Being offered bed-based provision was very important more so than the home-based provision that families stated was inconsistent and frequently cancelled.</p>	<p>Sheffield CCG plans to continue to commission bed-based provision for children and families.</p>
<p>Introducing some flexibility in how families can use NHS short-breaks provision would be welcomed by families</p>	<p>The aim of a future service is to provide flexibility in terms of allocation of nights and provision available. It is recognised that there is limited alternative provision for children in scope of this service review and the market needs to be grown. Wherever possible families will have flexibility in how they access their allocation for NHS funded short breaks through the commissioned service. However, the full extent to which this can be offered while ensuring that the service commissioned is viable and sustainable is being worked through.</p>
<p>Families require a consistent and reliable short breaks service</p>	<p>The disruption felt by families caused by closures at Ryegate House Respite Unit (night closures August 2017 and March 2018) and the frequently cancelled home-based provision impacts significantly on family life. Sheffield CCG wants to commission a service that</p>

	is financially and operationally viable in providing a quality, consistent and reliable service to families and children.
An emergency offer of short-break provision is important to some families.	A responsive service which is able to provide support in emergency situations is an aim of the service to be commissioned in future. However, very clear criteria would be used to determine what constitutes an emergency. Emergency allocation is yet to be determined, and any emergency offer would have to be in agreement with the provider.
Managing a Personal Health Budget is challenging whilst trying to care for a child with complex health needs	Whenever possible Sheffield CCG would directly commission short breaks care for families who want to use alternative providers for their short break care. Families would not have to manage a Personal Budget unless they felt this was the best option for them and would be supported in what this would involve.
Concerns were raised about cutting services	While the driver for service change is about creating equity in access, Sheffield CCG needs to ensure that provision is financially viable and sustainable for all children that require a service now and in future.
Limited choice of providers for children with complex health needs	It is recognised that there is limited choice for overnight bed-based provision for children with complex health needs. However, SCCG will be working with providers to ensure there is choice of provision including alternative options for short breaks that enable children to have further positive experiences and outcomes e.g. attendance at clubs and activities.
The one-week holiday was valued by those who receive it.	Allocation of nights on an annual basis will mean that a week's holiday is possible for all families, to be agreed with the service provider.

7.3 Following the public consultation feedback there have been two further changes made to future service requirements:

- The resource allocation principle (banding system) that will be developed to support a fairer and clearer allocation process for families will be a guideline. While it was the intention that a banding system would provide a guideline to support the decision making of a service offer, this needs to be clearly communicated to families
- Options for Personal Health Budgets will be simplified for the purpose of children's NHS funded short breaks. All families will receive a personalised care plan (following assessment) and the cost of the resource for their provision will be transparent and shared with the family. This will include families who wish to receive care by other providers that can be directly commissioned by SCCG. A Personal Health Budget will only be described to families when they receive a budget that they will directly manage. This is being discussed with colleagues at NHS England along with the feedback from the children's NHS funded short breaks pre-consultation engagement and public consultation to support this case and for further learning.

Recommendations / Next Steps

1. Meetings are scheduled from May 2018 to develop the service eligibility criteria, the single (joined-up) assessment, the assessment and re-assessment processes and

the banding/resource allocation guideline - to be finalised by 31 July 2018. All processes, assessment and criteria will be developed in partnership with stakeholders including representation from Sheffield Parent Carer Forum and parent representative from within the current service. Approval will be sort from the Children's NHS Funded Short Breaks Steering Group and SCCG Quality Assurance Committee

2. The principles of the mixed-model service requirements and the financial proposals will be shared with SC(NHS)FT by 30 May 2018
3. Negotiation of the financial and contract model and the development of a service specification will take place from June-August 2018 for service mobilisation from 1 September 2018
4. Children who receive both Children's Continuing Care packages and NHS funded short breaks will be identified to ensure *their* reviewed collaboratively as one package of care
5. New service model will be in operation from 1st September 2018. Families will through personalised assessment planning be fully supported through any change in service offer
6. Sheffield CCG and Sheffield City Council will continue to work together to ensure short breaks services are commissioned to provide further choice of provision and will accommodate the increasing complexity of children with complex and life limiting and life limiting conditions.

8. Action for Governing Body / Recommendations

8.1 The Governing Body is asked to:

- Consider whether the Public Consultation undertaken has provided enough opportunity and time for the public to feedback, and whether the feedback is enough to progress service change
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 - The mobilisation of a mixed model of service provision that includes overnight home- and bed-based provision and Personal Health Budgets.
- Approve the recommendation to progress service change

Paper prepared by Anna Clack, Commissioning Manager

On behalf of Mandy Philbin, Chief Nurse

8 May 2018