NHS Sheffield Clinical Commissioning Group

Equality Impact Assessment and Quality Impact Assessment Option 4

Title of policy or service:	Children's NHS Short-breaks: **Option 4** **This option 3 – Mixed Model of Provision including overnight bed-based, overnight home-based and Personal Health Budgets** This would involve the commissioning of overnight bed-based and home-based NHS short-breaks provision and Personal Health Budgets. In these circumstances, Personal Health Budgets (PHBs) involve an allocation of money from the NHS to enable a family to purchase their own short-break/respite care or alternative arrangements to meet the needs of their child. The service model could create a range of options including having part commissioned service provision and part Personal Health Budget.	
Name and role of officer/s completing the assessment:	Anna Clack – Commissioning Manager Richard Kennedy- Engagement Manager, Helen Mulholland – Engagement Manager	
Date of assessment:	20th December 2017	
Type of EIA completed:	**Initial EIA 'Screening'** ☒ ***or*** **'Full' EIA process** ☐	

1. Outline	
Give a brief summary of your policy or service • Aims • Objectives • Links to other policies, including partners, national or regional	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last 18 months SCCG has been working through a review of these services based on a case for change that includes: • An outdated service model of short-breaks/respite • Inequity of provision (some families receiving high packages of care while others get nothing) • The drive for greater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 A Needs Analysis has been conducted from the data and information provided in the Complex Needs Assessment (2014), the Child Disability Register (2015) and the SEND needs analysis (2015). In addition Ryegate House and Helena Team respite provision usage have been explored (from 2016- August 2017). Alongside this, we have compared the service offered to families in Sheffield to that offered to families in other parts of Yorkshire and statistical neighbours. This data and further exploration has shown us that: a) 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. b) 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. c) Sheffield allocates a comparatively high number of nights per child than other areas. d) There is a significant disparity in Sheffield between the allocation of nights in children's respite/short-breaks provision and that in adult provision e) Sheffield has a less joined up approach between the Local Authority and NHS than other areas. f) 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 A refresh of the Complex Needs Assessment is being undertaken by Sheffield City Council. There are 29 families accessing Ryegate House Respite Unit (as of December 2017) and 38 families have

been assessed as eligible for the Helena Nursing Service respite offer. However, approximately 54 children are thought to be currently accessing provision as some children access both NHS short-breaks services.

Of the children eligible for NHS short break provision from April 2017- December 2017:

Age

This includes children assessed as eligible for Ryegate House Respite Unit and the Helena Nursing Service Respite offer. Children aged under 3 years are eligible for the Helena Nursing Service offer:

Under 1 year	X 1 child
1 year	-
2 years	X 3 children
3 years	X 7 children
4 years	X 6 children
5 years	X 5 children
6 years	X 6 children
7 years	X 4 children
8 years	X 6 children
9 years	X 4 children
10 years	X 3 children
11 years	X 3 children
12 years	X 3 children
13 years	X 4 children
14 years	-
15 years	X 2 children
16 years	X 3 children
17 years	X3 children – in transition
18 years	X 2 young adults – transitioning
19 years	X1 young adult - transitioning

	Gender 34 males 33 females **Ethnicity (those who specified)** 9 Pakistani 40 White British 1 Black African 1 Somali 1 Bangladeshi 2 Libyan 2 Yemeni 1 Eritrean 2 Other European (x1 Italian and X1 German) 4 Any other mixed background **Language** From information provided by Ryegate House Respite Unit we also know that the language spoken by families includes: Urdu Punjabi Arabic Tigrinya Majority English as spoken/first language While there are currently approximately 54 children accessing NHS short-breaks we know there could be a further 60 children and young people (approximately) who could be in scope of a children's NHS short-breaks offer:

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/families who choose not to access
118	Total Information gathered from Sheffield Children's NHS Foundation Trust Helena Nursing Team and Ryegate House Respite Unit May 2017

Engagement and Feedback from Families

Engagement with families has taken place between August and November 2017; this included an engagement event and structured telephone interviews. 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 another set of structure telephone interviews that took place in February 2016 as part of an initial review of Ryegate House Respite Unit delivery.

The summary of feedback from the two engagement processes is as follows:

- 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 and 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, send 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 of 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. Scoring the level of importance for some of the questions has identified some key areas: • Families' think it is very important that NHS short-breaks provision is away from the home (in a bed based facility) (score 75/75) • Families' think that a reduction in nights would impact on their ability to care for their child and see

	this as very important (score 70/75) • Access to emergency nights is very important (score 70/75) • Flexibility in how families' choose their nights is very important (score 68/75)

Identifying impact:

- **Positive Impact:** will actively promote or improve equality of opportunity;
- **Neutral Impact:** where there are no notable consequences for any group;
- **Negative Impact:** negative or adverse impact causes disadvantage or exclusion. If such an impact is identified, the EIA should ensure, that as far as possible, it is either justified, eliminated, minimised or counter balanced by other measures. This may result in a 'full' EIA process.

	IMPACT				
LIKELIHOOD	1	2	3	4	5
1	1	2	3	4	5
2	2	4	6	8	10
3	3	6	9	12	15
4	4	8	12	16	20
5	5	10	15	20	25

LIKELIHOOD		IMPACT	
1	RARE	1	MINOR
2	UNLIKELY	2	MODERATE / LOW
3	MODERATE / POSSIBLE	3	SERIOUS
4	LIKELY	4	MAJOR
5	ALMOST CERTAIN	5	FATAL / CATASTROPHIC

Risk score	Category
1 - 3	Low risk (green)
4 - 6	Moderate risk (yellow)
8 - 12	High risk (orange)
15 - 25	Extreme risk (red)

2. Gathering of Information
This is the core of the analysis; what information do you have that might *impact on protected groups, with consideration of the General Equality Duty*.

(Please complete each area)	What key impact have you identified?								For impact identified (either positive and or negative) give details below:	
	Positive Impact			Neutral impact	Negative impact			Overall score	How does this impact, and what action, if any, do you need to take to address these issues?	What difference will this make?
	Likelihood	Impact	Overall		Likelihood	Impact	Overall			
Human rights				0					Non anticipated	
Age	4	3	12		2	2	4	High Positive 8	Those assessed as eligible for service are all aged between 0 and 19 years of age. 25% of children are aged 0-4 years, 37% are 5-9 years, 19% are 10-14 years and 16% are 15-19 years. Full analysis shows that there will be a larger impact on children aged 3-14 years. However, currently children aged under 2 cannot access Ryegate House Respite Unit. As children get older their health conditions may deteriorate resulting in increased levels of support for parents	Children from 0-19 years will be eligible for a range of service provision including overnight bed-based, home-based and Personal Health Budgets. Changing the service model to a more flexible service means that families could shape their packages of care to suit their child's age related needs and preferences e.g. a family with a child aged under

									and carers to manage. This could include the frequency of health intervention for the child/young person but also could be due to the child's increasing physical size. The introduction of a Carers assessment would fully take into consideration family needs and circumstances. Therefore young parents/carers and older parents/carers (who may have other caring responsibilities 'sandwich generation' - caring for young children and elderly parents at the same time) would be recognised. The resource allocation principle would also recognise and offer commissioned service provision (overnight home and/or bed based) and/or a budget more fairly and consistently. This service option could offer the greatest choice and flexibility for families to have a range of provision to suit their child's (and families) related needs and preferences. However the extent of choice and flexibility is influenced by the market that requires development. There are known gaps in provision for older young people	2 years may chose home-based provision and/or a Personal Health Budget to provide more informal caring arrangements e.g. by a family member.

									particularly those in transition. The market will have to be further stimulated to support this service model but can be grown alongside the service transition and mobilisation. A commissioned overnight bed-based and an overnight home-based provision can provide support for emergency nights and be able to respond in emergency circumstances (to some extent). This also supports the findings from the engagement with families, who place a high value on overnight bed-based provision for a "proper short-break".	
Carers	3	3	9		2	2	4	Moderate Positive 5	A new integrated assessment would take place (including a Carers Assessment joint process with Sheffield City Council) and an applied resource allocation principle would also recognise and offer resources/budget more fairly and consistently with consideration of the child and parent/carers circumstances. Not all parents and carers are aware of Personal Health Budgets so further work would be needed to support	Family and carers needs and circumstances would be fully taken into consideration. The process would also support re-assessment in response to changing needs and circumstances. Commissioned provision could provide support for emergency nights cover and when more informal PHB arrangements are in place.

									families. Some parents/carers would need additional support to be able to fully access services under this arrangement. A list of Any Qualified Providers (AQP) could support families in their decision making whilst offering an assurance to SCCG over the quality of service offer. The security of commissioned provision can help support families who would like to explore the options for more personalised care. Personal Health Budgets could offer more choice and flexibility for families to purchase their own short breaks provision to suit their child's (and families) related needs and preferences. However the extent of choice and flexibility is influenced by the market that requires development. There are known gaps in provision for older young people particularly those in transition. The market will have to be further stimulated to fully support PHBs. However, this can be grown overtime with support of commissioned provision. The extent to which families take-up PHBs is a risk to both SCCG and the	

									commissioned provision. Without a guaranteed and sustainable income, service providers are put at risk.	
Disability	4	4	16		2	2	4	High Positive 12	Children accessing NHS short-breaks provision have a range of different disabilities. However primarily the children who attend services have complex neuro-disability and/or life limiting and life threatening conditions. A new integrated assessment would take place (including a Carers Assessment joint process with Sheffield City Council). This alongside a published resource allocation principle would fully recognise the needs within the family and offer resources/budget more fairly and consistently with consideration of disability of both the child, parent/carers and sibling(s). A range of provision could offer more choice and flexibility for families to access provision when having the option to purchase their own short breaks provision to suit their child's (and families) related needs/disabilities	Family and carers needs and circumstances would be fully taken into consideration e.g. disabilities of family members including physical, learning and Long-Term-Conditions (including mental ill-health). The process would also support re-assessment in response to changing family/carer needs and circumstances. Emergency support would be provided (as much as possible) by commissioned provision.

									and preferences. For PHBs the extent of choice and flexibility is influenced by the market that requires development. The extent to which families take-up PHBs is a risk both to SCCG and the commissioned provision. Without a guaranteed and sustainable income, service providers are put at risk. This could result in closure of provision.	
Sex					2	2	4	Moderate Negative -4	There is currently a fairly equal split between children assessed as eligible for NHS short-breaks - 51% are male and 49% are female. A new integrated assessment would take place (including a Carers Assessment joint process with Sheffield City Council). This alongside a published resource allocation principle would fully recognise the needs within the family and offer resources/budget more fairly and consistently with consideration of gender. A range of provision could offer more	Changing the service model to a mixed model offers the greatest flexibility and the offer of an overnight bed-based provision that families say they need for a “proper short-break”. Family and carers needs and

									choice and flexibility for families to access provision when having the option to purchase their own short breaks care. Not all parents and carers are aware of Personal Health Budgets so further work would be needed to support families. Some parents/carers would need additional support to be able to fully access services under this arrangement. A list of Any Qualified Providers (AQP) could support families in their decision making whilst offering an assurance to SCCG over the quality of service offer. The extent of choice and flexibility is influenced by the market that requires development. The full extent of emergency support would have to be explored further, particularly when the Personal Health Budget is supporting more informal caring arrangements e.g. childminder. If the arrangement broke down or was cancelled this would place a significant burden on parents/carers who are primarily women.	circumstances would be fully taken into consideration. The process would also support re-assessment in response to changing family/carer needs and circumstances. Emergency support would be provided (as much as possible) by commissioned provision.

									The extent to which families take-up PHBs is a risk to both SCCG and the commissioned provision. Without a guaranteed and sustainable income, service providers are put at risk.	
Race	4	4	16		2	2	2	High Positive 14	Of the children assessed as eligible for children's NHS short-breaks: 63% are White British, 14% are Pakistani, 6% any other mixed background, 3% are Libyan, 3% Yemeni, 3% are other European, 1.5% are Somali, 1.5% are Black African, 1.5% are Bangladeshi, and 1.5% Eritrean. BME communities are underrepresented in services for disabled children (Sheffield City Council Complex Needs Assessment 2014). This is also reflected nationally. A new integrated assessment would take place (including a Carers Assessment joint process with Sheffield City Council) to sensitively consider the cultural needs and preferences of families. The resource allocation principle would also	Family and carers needs and circumstances would be fully taken into consideration. The process would also support re-assessment in response to changing needs and circumstances. However, the full extent of emergency support would have to be explored further, particularly when informal caring arrangements are in place.

									recognise and offer resources/budget more fairly and consistently. Not all parents and carers are aware of Personal Health Budgets so further work would be needed to support families. Some parents/carers would need additional support including translation and advocacy services to be fully informed and be supported to access either commissioned services or provision via a Personal Health Budget (or both). Personal Health Budgets could offer more choice and flexibility for families to purchase their own short breaks provision to suit their child's (and families) related needs and the families' cultural preferences. However the extent of choice and flexibility is influenced by the market that requires development. Further exploration of reasons why families' may not chose to access provision is needed. The extent to which families take-up PHBs is a risk to both SCCG and the commissioned provision. Without a guaranteed and sustainable income,	More choice in service offer may encourage families who do not currently access provision under the existing provision arrangements. Families who would like children to remain at home can chose to do so with an allocated Personal Health Budget and access care from someone they know e.g. family member. Choice of provision could support more families to access the support they need.

									service providers are put at risk. Engagement with families has reflected high value placed on the service received by Ryegate House Respite Unit but would like more flexibility in how they access. Having a transparent process and consistent service offer is essential for families who need support. Services should be culturally sensitive and offer advocacy and translation services. In addition services should be ensuring consistent and appropriate support is available to all families. A list of Any Qualified Providers could ensure these quality criteria as part of a service specification. However, more informal caring arrangements make this quality assurance more challenging.	
Religion or belief				0						
Sexual orientation				0						
Gender reassignment				0						
Pregnancy and maternity	2	4	8		2	2	4	Moderate Positive 4	A new integrated assessment would take place (including a Carers Assessment joint process with	Family and carers needs and circumstances would be fully taken into consideration. The

									Sheffield City Council). This alongside the resource allocation principle would also recognise and offer resources/budget more fairly and consistently with consideration of changing family circumstances. Personal Health Budgets could offer more choice and flexibility for families to purchase their own short breaks provision to suit changing family circumstances. However the extent of choice and flexibility is influenced by the market that requires development. The market will have to be further stimulated to support this service model but can be grown alongside the service transition and mobilisation. The current services delivered by SC (NHS) FT may not be able to sustain themselves without a guaranteed income. This could put the current service provision at risk. Engagement with families has reflected high value placed on the service received by Ryegate House Respite Unit but would like more flexibility in how they access.	process would also support re-assessment in response to changing needs and circumstances e.g. parent/carer pregnancy. However, the full extent of emergency support would have to be explored further, particularly when informal caring arrangements are in place.

Marriage and civil partnership (only eliminating discrimination)										
Other relevant groups	3 3 4 3	4 4 4 4	12 12 16 12	2	2 2 2 2	2 2 2 2	4 4 4 4	High Positive 8 High Positive 8 High Positive 12 High Positive 8	***Lone-parents/carers*** About a third of disabled children live with a lone parent (Hogan et al 2012). ***Poverty*** Families who have children with disabilities are more likely to be subject to financial pressures and poverty. ***Employment*** The current children's NHS short-break service allocation may not be supporting employment and the seeking of employment. ***Siblings*** Through engagement with families most reported that access to children's NHS short-breaks enabled them to spend time with their other children, some of whom have disabilities and additional needs.	Family and carers needs and circumstances would be fully taken into consideration. The process would also support re-assessment in response to changing needs and circumstances e.g. lone parents and siblings. However, the full extent of emergency support would have to be explored further, particularly when informal caring arrangements are in place.

SCORE								Moderate Positive 7.5		
HR Policies only: Part or Fixed term staff										

Having detailed the actions you need to take please transfer them to onto the action plan below.

3. Action plan				
Issues/impact identified	**Actions required**	**How will you measure impact/progress**	**Timescale**	**Officer responsible**
To be completed following consultation				

4. Monitoring, Review and Publication				
When will the proposal be reviewed and by whom?	**Lead / Reviewing Officer:**		**Date of next Review:**	

To fulfil the requirements of the Public Sector Equality Duty, we need to capture how due regard has been shown to the need to eliminate discrimination, ensure equality for people with protected characteristics and promote good relations between all people in the community.

Please could you therefore provide the following information from your planning processes:

Confirm that you have used local demographic data to plan your approach to delivering services	Local demographic data has been used in the development of this service option. This will be explored further once a service option has been decided to plan the approach to service delivery.
Summarise steps taken to ensure equal access to services and treatment for people with a protected characteristic, or sectors of the community with specific needs	This will be fully worked through, following consultation, for the service option that best meets the needs of children and families.

PART TWO: QUALITY IMPACT ASSESSMENT OPTION 4

NHS
Sheffield
Clinical Commissioning Group

Once form is completed please email to Project Lead		**Scheme Number:**		
Quality Impact Assessment				
Scheme Name	**Option 4**:- **Mixed Model of Provision including overnight bed-based, overnight home-based and Personal Health Budgets**			
Scheme Overview	This would involve the commissioning of overnight bed-based and home-based NHS short-breaks provision and Personal Health Budgets. In these circumstances, Personal Health Budgets (PHBs) involve an allocation of money from the NHS to enable a family to purchase their own short-break/respite care or alternative arrangements to meet the needs of their child. The service model could create a range of options including having part commissioned service provision and part Personal Health Budget.			
Project Lead	Anna Clack – Commissioning Manager	Portfolio	Quality	
Clinician Completing QIA	Janet Beardsley Senior Quality Manager			
Patient Safety For example could the proposal/action impact positively or negatively on any of the following: safety, systems in place to safeguard patients to prevent harm, including infections, delivery of safe clinical standard of care?	Continuing to work with Sheffield Children's NHS Foundation Trust (SCFT) the provider of children's NHS short breaks services (both House Respite Unit and a home respite offer) is positive as the Trust has robust policies and processes in place to safeguard patient safety. SCFT are committed to improving the quality and safety of services and have devised 'Ward Quality' assurance framework by which Ryegate House Respite Unit will be reviewed. The Helena Nursing service respite offer (who routinely provides short break care during the day up to 10pm at night) also works to assurance frameworks and nursing staff are governed by professional standards e.g. Nursing and Midwifery Council.	Impact Positive	Likelihood	Score

	Within the service contract (taken from the standard NHS contracts information) SC (NHS) FT responds to recommendations that arise from any audit, serious incident report, or patient safety incident report to continually improve standards of care. SCFT as a provider of NHS short-breaks services is required to be fully compliant with CQC essential standards. For families wanting to explore other options for short breaks Personal Health Budgets could be introduced. In this option the exploration of Personal Health Budgets can be done at the same time as accessing the current quality short break provision delivered by SC (NHD) FT. To safeguard the quality of the provision options available to children and families, a list of suitably qualified providers could be developed with providers who meet service specific requirements including patient safety and clinical effectiveness. This would assure Sheffield Clinical Commissioning Group over the quality of the service provided to children families. For families who may choose to directly employ a personal assistant (with a direct payment Personal Health Budget) to provide some or all of their short break care, the family would be the employer and responsible for employment arrangements (subject to employment legislation), providing insurance indemnity, training (including Health and Safety issues) and other necessary requirements including DBS checking. In these circumstances governance and case management arrangements would have to be in place to assure quality including patient safety. Agreement on these arrangements would have to be worked through.	Positive Neutral Negative 3	4	High Risk 12

	There are cases of children currently accessing NHS short breaks services whose condition is often unstable and who require round the clock, consistent and responsive care. If the arrangement of an employed worker (by the family) broke down this would not only be a stressor for the family but would also place added strain on the health and social care system. However with this option, there is the opportunity for the commissioned provision provided by SCFT to provide responsive short breaks care in these circumstances (where possible). Future planning and assessment discussions could also determine which provision option (e.g. SCFT commissioned provision of Personal Health Budget options) would be in the best interest of the child when their health condition is unstable or deteriorating. This could be considered positive if clear contingency pathways are built in for this situation, so it becomes part of the pathway rather than providers responding to reactive situations. This option sustains an overnight bed-based provision in a very limited market. Engagement with families currently accessing NHS short breaks services identified that overnight bed-based service provision away from home is highly valued by families to enable them to have a "proper short break". This option also allows for market growth to develop to provide greater choice of service options whilst sustaining quality and safe provision.	Neutral Positive		

Clinical Effectiveness For example could the proposal/action impact positively or negatively on evidence based practice, clinical leadership, clinical engagement and/or high quality standards or any other areas?	SC (NHS) FT as the current provider of NHS short-breaks services in Sheffield works to clinical effectiveness standards with clear governance arrangements and risk management processes. Sustaining this provision is positive. All services provided by SCFT are required take part in clinical audit and effectiveness activities. Compliance with clinical policies and procedures is all monitored; this includes infection control and medicines management. Service evaluation is also integral to the clinical effectiveness standards within SC (NHS) FT and includes patient involvement and equity compliance. To allow families more choice of short breaks provision the option of Personal Health Budgets could, via a new published offer of commissioning care, stimulate the market whilst sustaining the clinically effective provision provided by SC (NHS) FT. There are other providers in the market to provide short-breaks care to families in Sheffield, the market is limited particularly for overnight bed-based provision. To assure clinical effectiveness and high quality standards a list of suitably qualitied providers could be developed who meet service specific requirements including patient safety and clinical effectiveness. This would assure Sheffield Clinical Commissioning Group (and families) over the quality of the service provided to children. Case management and governance arrangements need to be in place to oversee direct payment Personal Health Budgets and the care provided. These arrangements would need to be worked through and agreed.	Positive Positive Positive Neutral Neutral		

Patient Experience For example could the proposal/action impact positively or negatively on any of the following: positive survey results from patients, patient choice, personalised and compassionate care?	Families currently accessing NHS short breaks services place high value bed-based provision for a 'proper' short-break. Given choice many families state that they would chose Ryegate House Respite Unit and place value on the relationship they have with staff. This option has the potential to offer the most choice and flexibility whilst recognising that families would chose Ryegate House Respite Unit for their overnight bed-based provision. However, the extent of choice is influenced by the market which is currently limited. There have been no complaints about NHS short breaks services to PALS or SC (NHS) FT complaints. Engagement with families currently accessing Children's NHS short breaks services (from SCFT) also identified that families hadn't heard much about Personal Health Budgets (PHs) and have little or no understanding of what it is. Some families would like more information about PHBs to support flexibility and choice in how they use their allocation of short breaks provision. Sustaining the current NHS short breaks services provided by SC (NHS) FT would allow time and opportunity for parents and carers to be made fully aware of the scope of Personal Health Budgets. In addition provision could be put in place for parents and carers who would need additional support including translation and advocacy services to be fully informed about and able to access Personal Health Budgets.	Positive Positive Positive Neutral Neutral Positive		

	The option of Personal Health Budgets could offer more choice and flexibility for families' to purchase their own short breaks provision to suit their child's related needs and cultural preferences. However, the extent of choice and flexibility is influenced by the market that requires development. Having a single assessment process for NHS short breaks that is joined up with other assessment processes (including carers assessment) and having a published resource allocation principle, should ensure equity in provision. It is also anticipated that enabling families to have more choice in short breaks services may encourage some families who don't currently access to do so. This should have a positive impact on patient choice, surveys and personalised and compassionate care. SCCG with support of key stakeholders will have engaged with our population through a range of public consultation events and opportunities.	Neutral Positive Positive Positive		
Prevention For example could the proposal/action impact positively or negatively on promotion of self care and health inequality?	Through sustaining NHS short breaks services provided by SC (NHS) FT the positive prevention work carried out could be maintained. The short breaks services are a source information, advice and support for families to maintain care outside the delivered short-breaks hours. Strategies and learning are shared with families (to promote self-care) by Ryegate House Respite Unit and the Helena Nursing Team to ensure safe and quality care is consistently delivered to ensure the best outcomes for the child.	Positive		

	Equity in provision should be improved thought the introduction of a joined up assessment processes, carers assessment and having a published resource allocation principle. Having more choice in provision and a published offer, may encourage families to access (and benefit from the opportunity to enhance the care management of their child's condition and outcomes) who don't already do so. Case management and governance arrangements would need to be agreed for Personal Health Budget options and systems in place to support the delivery of care for families and self care management. Systems would also need to be in place to ensure opportunity in access including BME communities who are underrepresented in in services for disabled children (both locally and nationally) to prevent widening health inequalities.	Positive Positive Neutral Positive		
Productivity and Innovation For example could the proposal/action impact positively or negatively on the best setting to deliver best clinical and cost effective care' eliminating any resource inefficiencies; improved care pathway?	Sustaining NHS short breaks provision provided by SC (NHS) FT should ensure clinically effective and efficient care continues e.g. children who have been supported by NHS breaks services that have resulted in a significant reduction in admittance into hospital and requiring Intensive Care Unit (ITU) support. Reviewing the costs for NHS short-breaks, providing more care for children considered eligible and stimulating the market for service providers, may contribute to a more cost-effective service delivery. Children accessing NHS short breaks services should continue to have medicine reviews, assessment and	Positive		

	observations during their stay/care delivery if this supports cost effective and efficient care (rather than children having to attend hospital) and could be commissioned to do so. For families wanting to explore other options for short breaks Personal Health Budgets could be introduced. In this option the exploration of Personal Health Budgets can be done at the same time as accessing the current quality short break provision delivered by SC (NHD) FT. To safeguard the quality of the provision options available to children and families, a list of suitably qualified providers could be developed with providers who meet service specific requirements including patient safety and clinical effectiveness. This would assure Sheffield Clinical Commissioning Group (and families) over the quality of the service provided to children families including clinical effectiveness. For families who may choose to directly employ a personal assistant to provide short breaks care, the family would be responsible for employment arrangements (subject to employment legislation), providing insurance indemnity, training (including Health and Safety issues) and other necessary requirements including DBS checking. While there are options for managed accounts to support direct employment this arrangement has been worked through. In both these circumstances (direct employment or a managed account) governance and case management arrangements would have to be in place to assure quality including patient safety. Agreement on these arrangements would have to be worked through. There are no systems currently in place to support these arrangements.	Positive Positive Negative 2	3	6 Moderate Risk

	There is a financial risk to SCCG in trying to sustain commissioned provision in a block contract (provision at SC(NHS)FT) while offering Personal Health Budgets. Financial modelling would carefully review this but if more people than anticipated choose Personal Health Budgets than the commissioned provision this could contribute to an overspend on the budget. Case management, governance arrangements and emergency/responsive support would need to be in place to oversee direct payment Personal Health Budgets and the care provided. These arrangements would need to be worked through and agreed. The patient's needs are quite likely to change through life, and they may require additional secondary care at various times. There would need to be an appropriate pathway(s) for seamless and consistent care from all providers. These pathways will need to be worked through.	Negative 2 Neutral Positive	4	6 Moderate Risk
Vacancy Impact For example could the proposal/action impact positively or negatively as a result of staffing posts lost?	If more families take Personal Health Budgets this may reduce the usage of the current NHS short breaks services. This could result in posts being lost due to the services having a reduction in demand. There may be some mitigation through providing different opportunities for staff to be utilised so there skills won't be lost.	Negative 2	3	6 moderate Risk

Mitigation	Details This option provides an opportunity to sustain the current quality provision for children's NHS short breaks (valued highly by families) whilst stimulating the market to provide more choice and flexibility. It also allows time for thee governance and case management arrangements processes to be established top support the options for Personal Health Budgets – that families would also like to explore. Robust financial modelling will be required that fully considers offering both commissioned service provision and Personal Health Budgets to ensure the total spend of care remains within budget.			
	Overall Risk Score- Based on an average of the scores above	7.5		

Conclusion

Total Overall Risk Score for Option 3

SCORE	30

Appendix 1

LIKELIHOOD \ IMPACT	1	2	3	4	5
1	1	2	3	4	5
2	2	4	6	8	10
3	3	6	9	12	15
4	4	8	12	16	20
5	5	10	15	20	25

LIKELIHOOD		IMPACT	
1	RARE	1	MINOR
2	UNLIKELY	2	MODERATE / LOW
3	MODERATE / POSSIBLE	3	SERIOUS
4	LIKELY	4	MAJOR
5	ALMOST CERTAIN	5	FATAL / CATASTROPHIC

Risk score	Category
1 - 3	Low risk (green)
4 - 6	Moderate risk (yellow)
8 - 12	High risk (orange)
15 - 25	Extreme risk (red)

Working with you to make Sheffield HEALTHIER

Appendix B

NHS Sheffield Clinical Commissioning Group

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.

NHS Sheffield Clinical Commissioning Group

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

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

NHS Sheffield Clinical Commissioning Group

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.

5

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.

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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.

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Have your say

Complete the survey

Complete the feedback form online at 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

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 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?

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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

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:

Working with you to make Sheffield HEALTHIER

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	

What is your gender?					
Female		Male		Prefer not to say	

Transgender					
Is your gender identity different to the sex you were assumed to be at birth?					
Yes		No		Prefer not to say	

What is your age?		
	years	Prefer not to say

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	

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	

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.

NHS
Sheffield
Clinical Commissioning Group

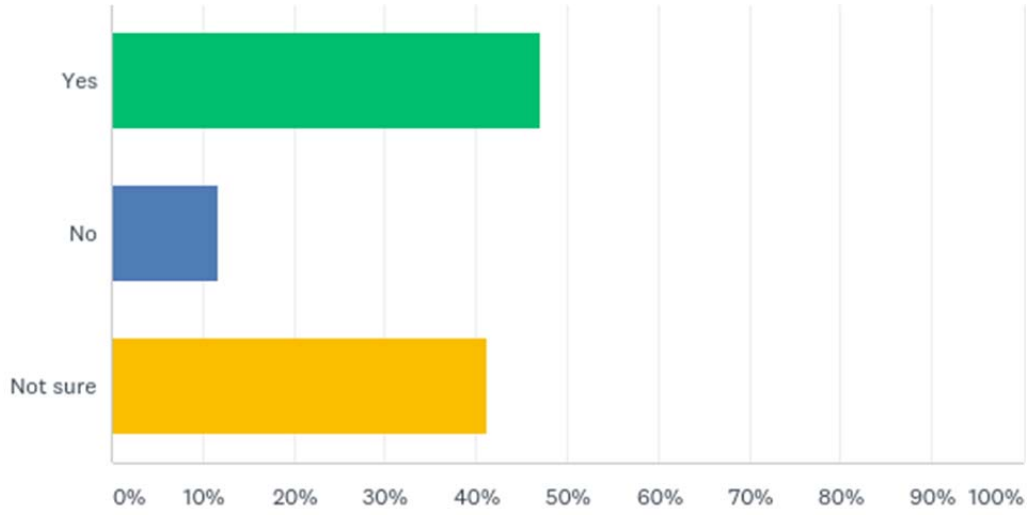
If you have any further questions, big or small, about this consultation:

Visit the website: www.sheffieldccg.nhs.uk
Call us: 0114 305 1028
Email us: SHECCG.ChildrensCommissioning@nhs.net
Twitter: @NHSSheffieldCCG
Facebook: /NHSSheffieldCCG
Write to us: NHS Sheffield CCG, 722 Prince of Wales Road, Sheffield S9 4EU

Appendix C

Q2: 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 of the consultation document)

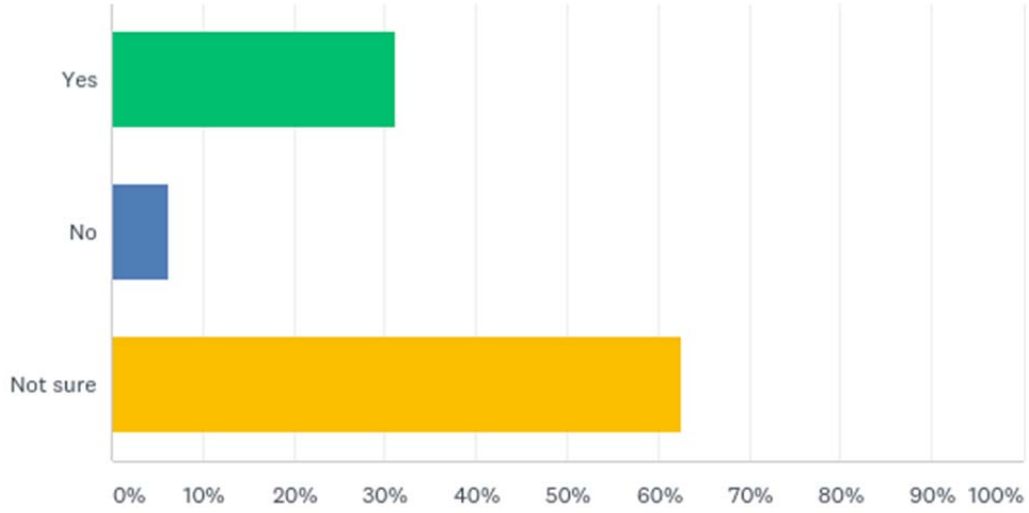
Answered: 17 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	47.06%	8
No	11.76%	2
Not sure	41.18%	7
TOTAL		17

Q4: Do you think introducing an allocation banding guideline for allocating short breaks would help make this clearer and fairer for all families? (Information on page 9 & 10 of the consultation document)

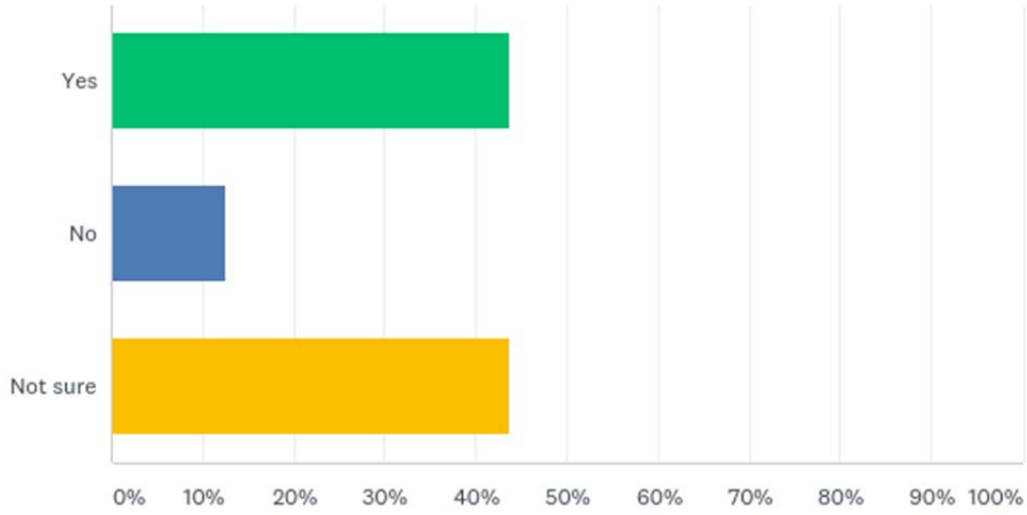
Answered: 16 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	31.25%	5
No	6.25%	1
Not sure	62.50%	10
TOTAL		16

Q6: Do you think the recommended service model will give families more choice and flexibility? (Information on page 12 of the consultation document)

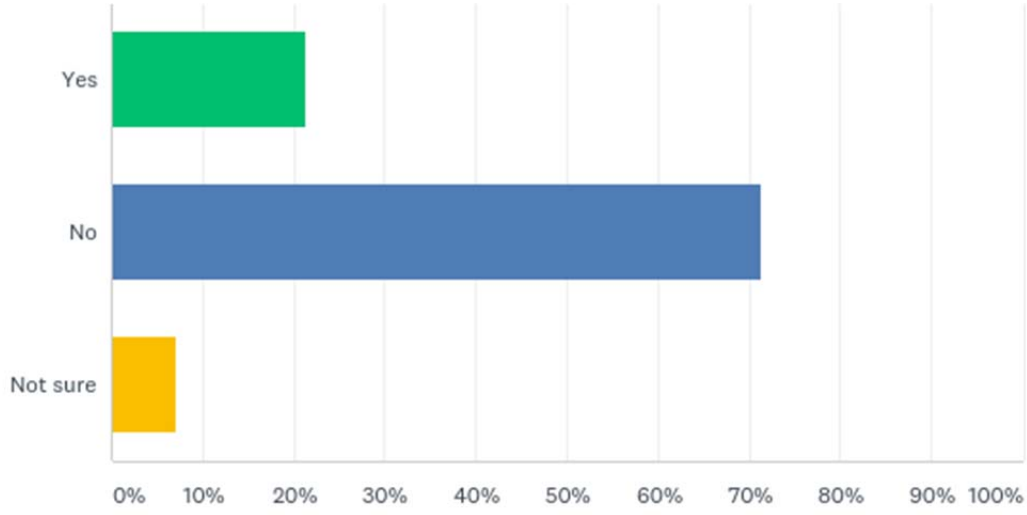
Answered: 16 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	43.75%	7
No	12.50%	2
Not sure	43.75%	7
TOTAL		16

Q7: Do you think one of the alternate models we looked at would be better than the one we have recommended? (Information on page 11 of the consultation document)

Answered: 14 Skipped: 3

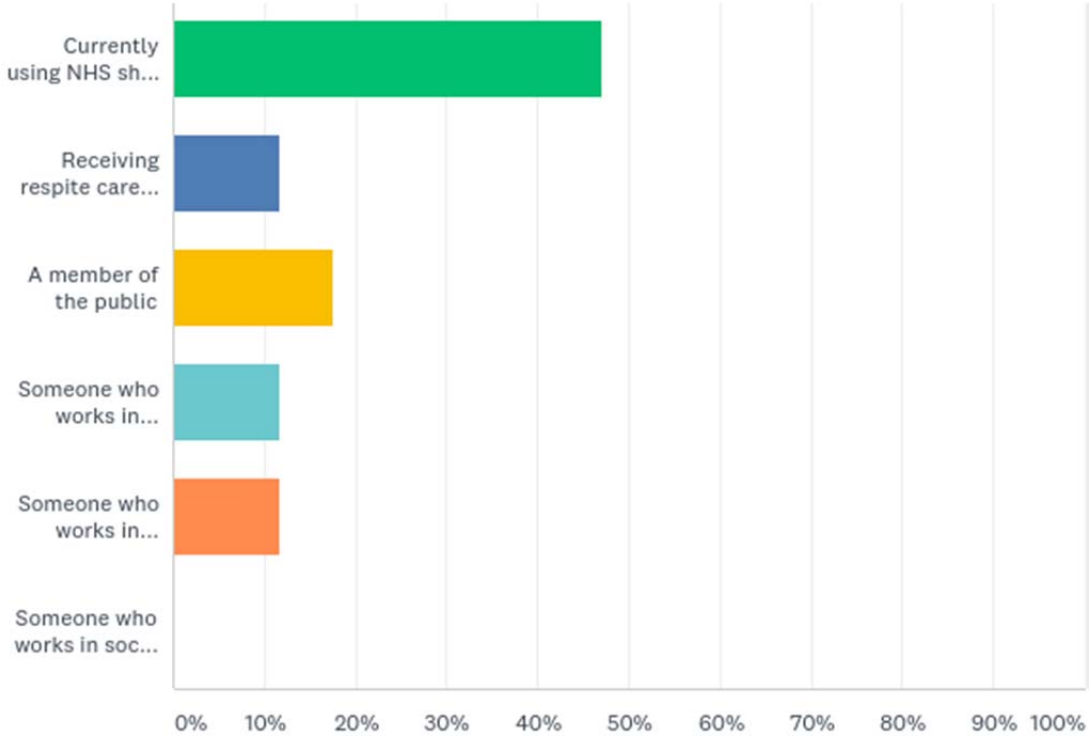


ANSWER CHOICES	RESPONSES	
Yes	21.43%	3
No	71.43%	10
Not sure	7.14%	1
TOTAL		14

Demographics

Q10: Please tell us if you are:

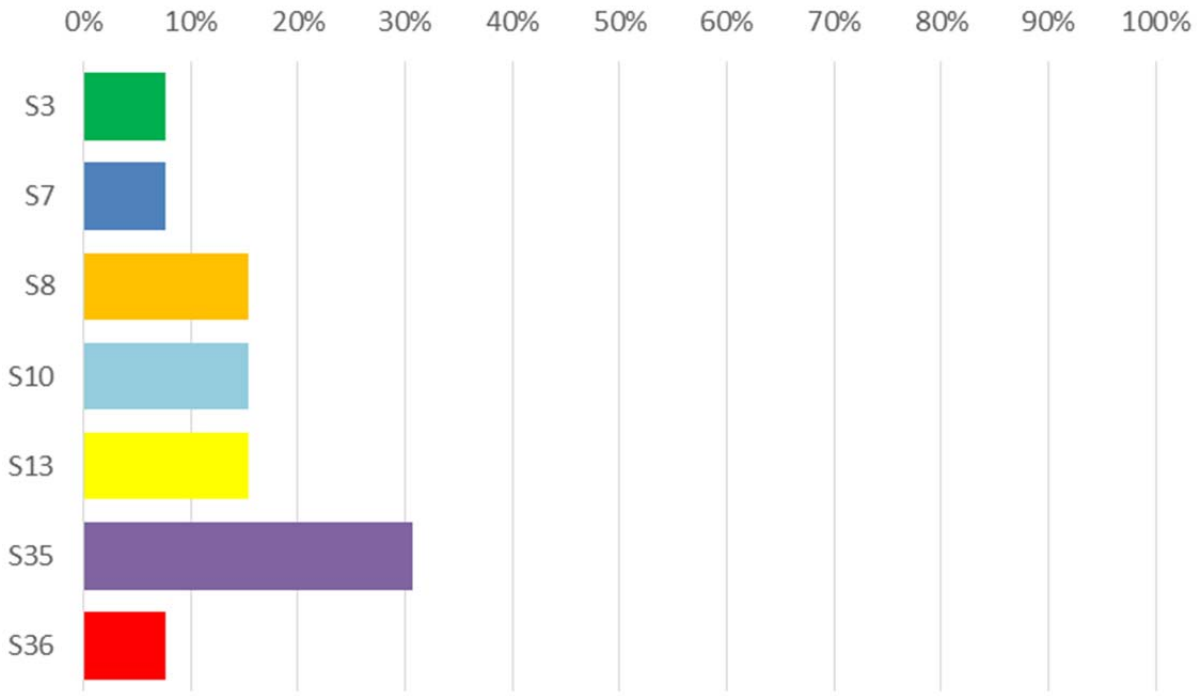
Answered: 17 Skipped: 0



ANSWER CHOICES	RESPONSES	
Currently using NHS short breaks (respite) for your child. If yes, please tell us which service(s) you use in the box below	47.06%	8
Receiving respite care for your child from Sheffield City Council	11.76%	2
A member of the public	17.65%	3
Someone who works in primary care	11.76%	2
Someone who works in secondary care	11.76%	2
Someone who works in social care.	0.00%	0
TOTAL		17

Q11: Please tell us the first part of your postcode (e.g. S9, S35)

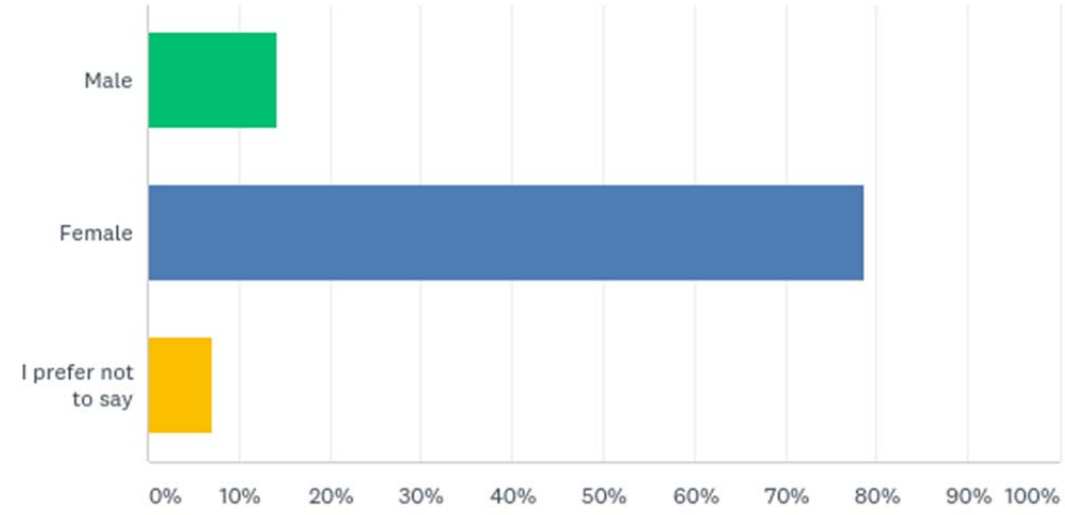
Answered: 13 Skipped: 4



ANSWER CHOICES	RESPONSES	
S3	7.69%	1
S7	7.69%	1
S8	15.38%	2
S10	15.38%	2
S13	15.38%	2
S35	30.77%	4
S36	7.69%	1
TOTAL		13

Q12: What is your gender?

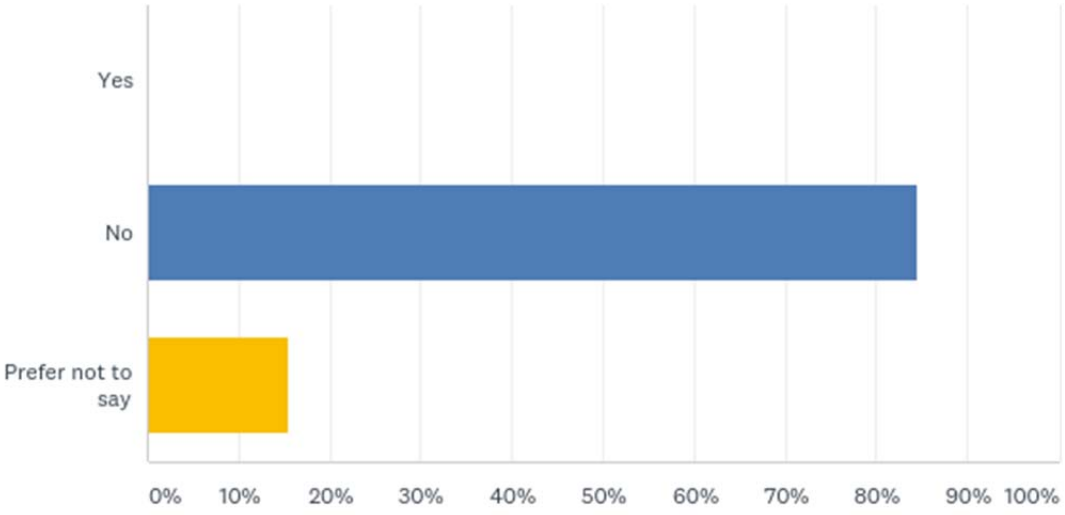
Answered: 14 Skipped: 3



ANSWER CHOICES	RESPONSES	
Male	14.29%	2
Female	78.57%	11
I prefer not to say	7.14%	1
TOTAL		14

Q13: Is your gender identity different to the sex you were assumed to be at birth?

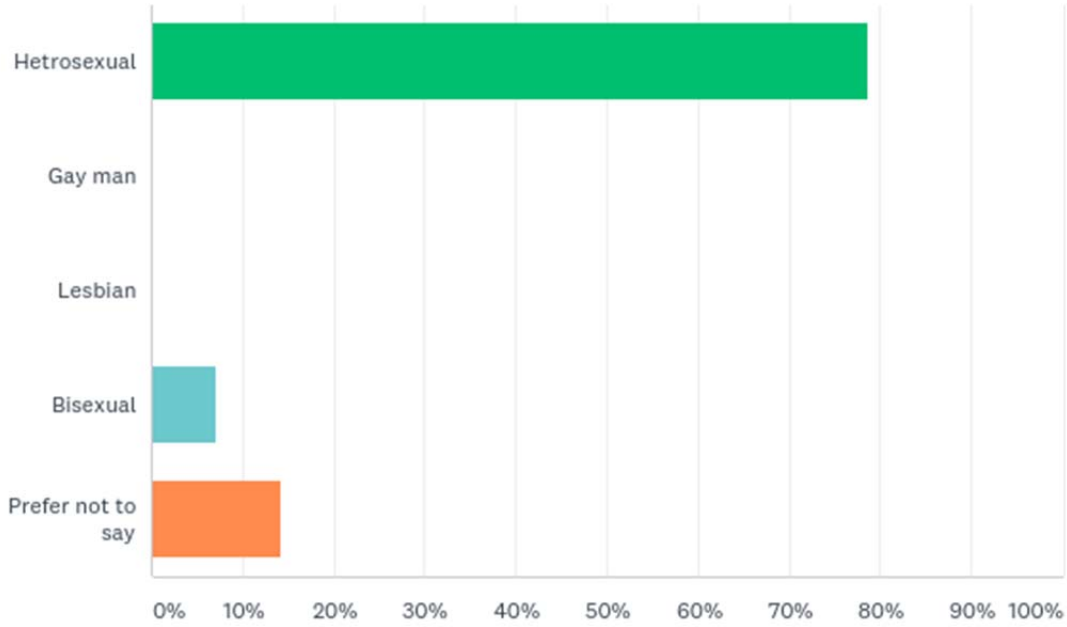
Answered: 13 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	0.00%	0
No	84.62%	11
Prefer not to say	15.38%	2
TOTAL		13

Q14: What is your sexual orientation?

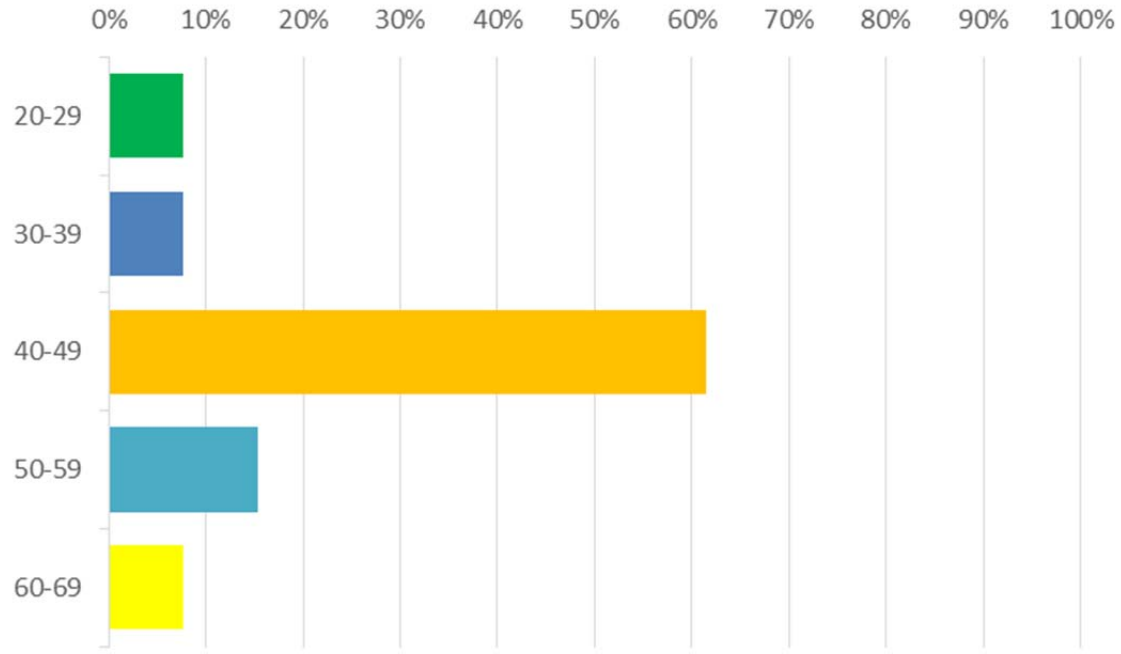
Answered: 14 Skipped: 3



ANSWER CHOICES	RESPONSES	
Hetrosexual	78.57%	11
Gay man	0.00%	0
Lesbian	0.00%	0
Bisexual	7.14%	1
Prefer not to say	14.29%	2
TOTAL		14

Q15: What is your age?

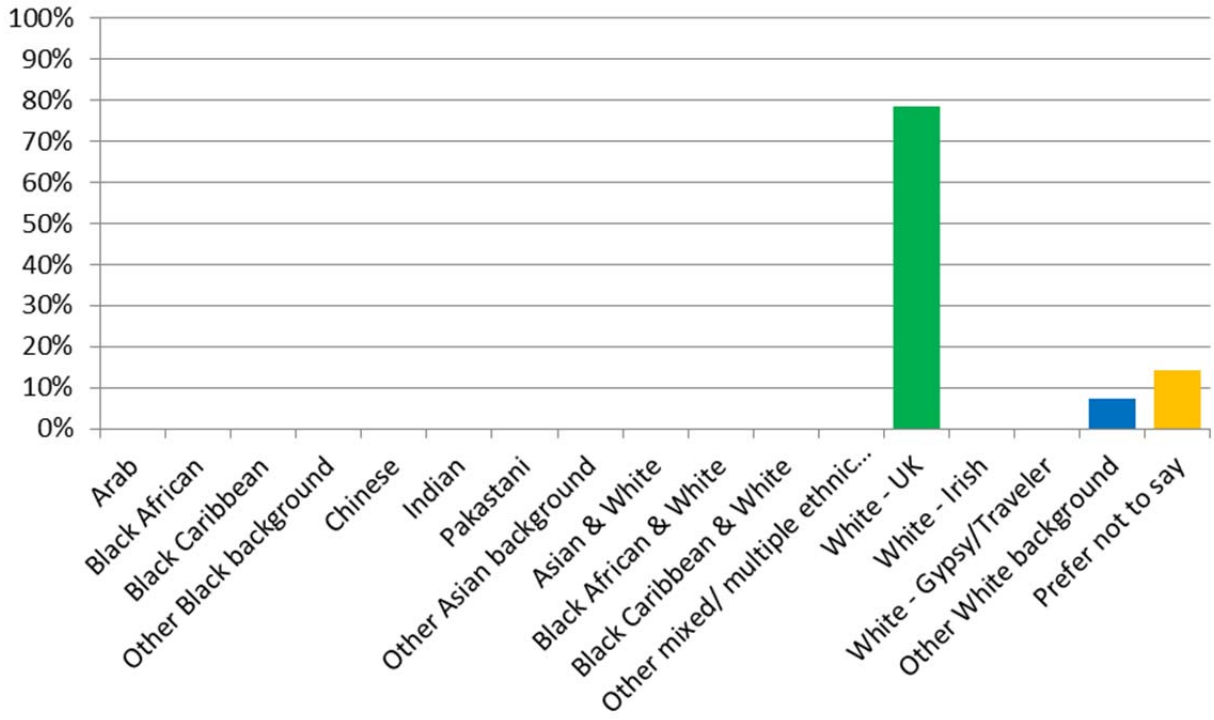
Answered: 13 Skipped: 4



ANSWER CHOICES	RESPONSES	
20-29	7.69%	1
30-39	7.69%	1
40-49	61.54%	8
50-59	15.38%	2
60-69	7.69%	1
TOTAL		13

Q16: What is your ethnic background?

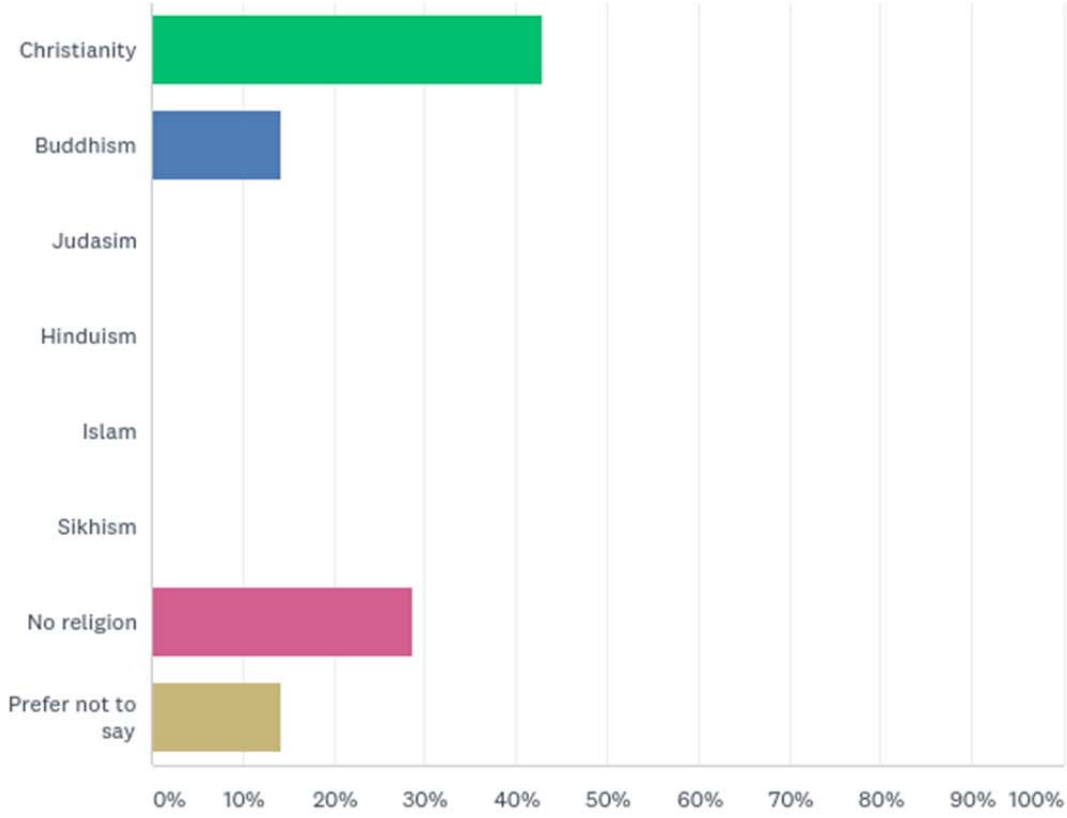
Answered: 14 Skipped: 3



ANSWER CHOICES	RESPONSES	
Arab	0.00%	0
Black African	0.00%	0
Black Caribbean	0.00%	0
Other Black background	0.00%	0
Chinese	0.00%	0
Indian	0.00%	0
Pakastani	0.00%	0
Other Asian background	0.00%	0
Asian & White	0.00%	0
Black African & White	0.00%	0
Black Caribbean & White	0.00%	0
Other mixed/ multiple ethnic background	0.00%	0
White - UK	78.57%	11
White - Irish	0.00%	0
White - Gypsy/Traveler	0.00%	0
Other White background	7.14%	1
Prefer not to say	14.29%	2
TOTAL		14

Q17: Do you consider yourself to belong to any religion?

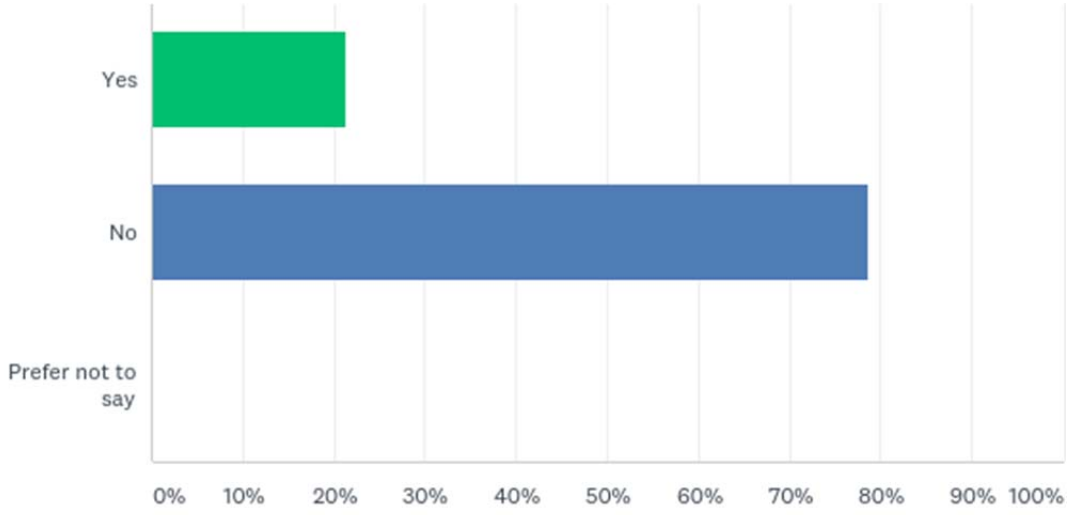
Answered: 14 Skipped: 3



ANSWER CHOICES	RESPONSES	
Christianity	42.86%	6
Buddhism	14.29%	2
Judasim	0.00%	0
Hinduism	0.00%	0
Islam	0.00%	0
Sikhism	0.00%	0
No religion	28.57%	4
Prefer not to say	14.29%	2
TOTAL		14

Q18: Do you consider yourself to have a disability?

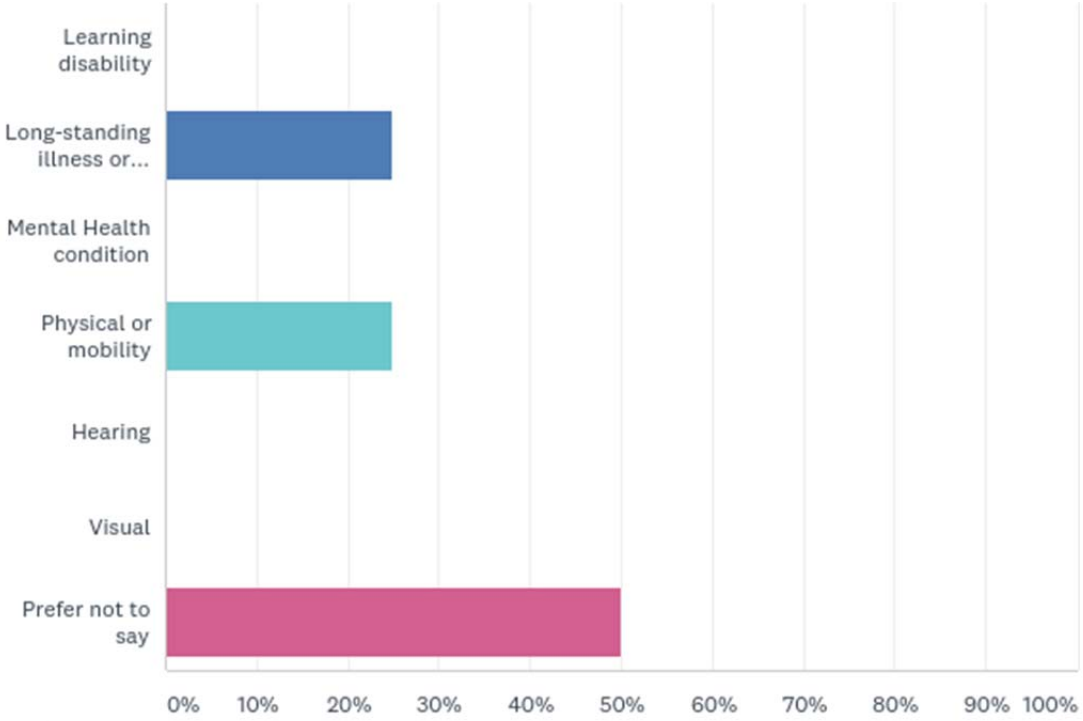
Answered: 14 Skipped: 3



ANSWER CHOICES	RESPONSES	
Yes	21.43%	3
No	78.57%	11
Prefer not to say	0.00%	0
TOTAL		14

Q19: If yes above, what type of disability do you have? (Tick all that apply)

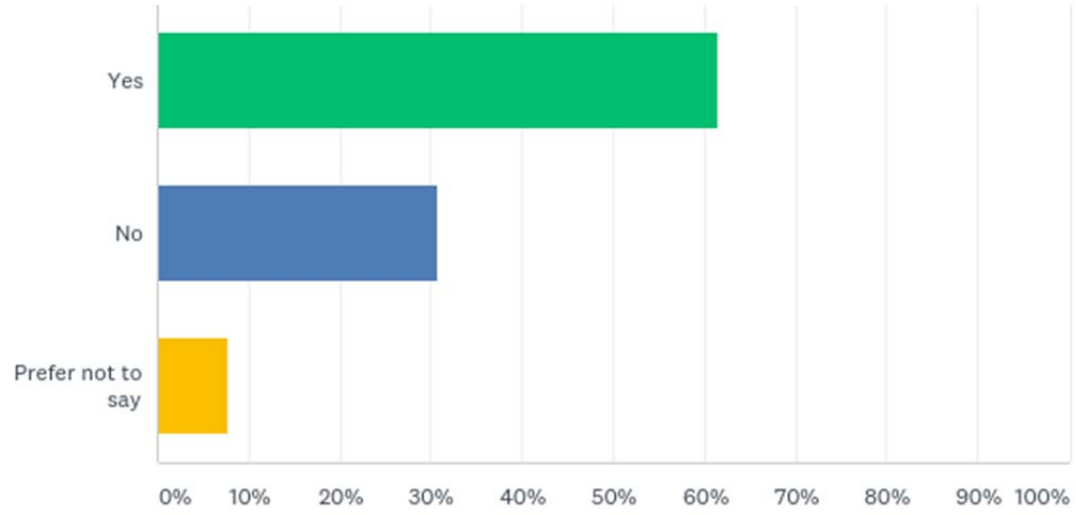
Answered: 4 Skipped: 13



ANSWER CHOICES	RESPONSES	
Learning disability	0.00%	0
Long-standing illness or health condition	25.00%	1
Mental Health condition	0.00%	0
Physical or mobility	25.00%	1
Hearing	0.00%	0
Visual	0.00%	0
Prefer not to say	50.00%	2
TOTAL		4

Q20: 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)

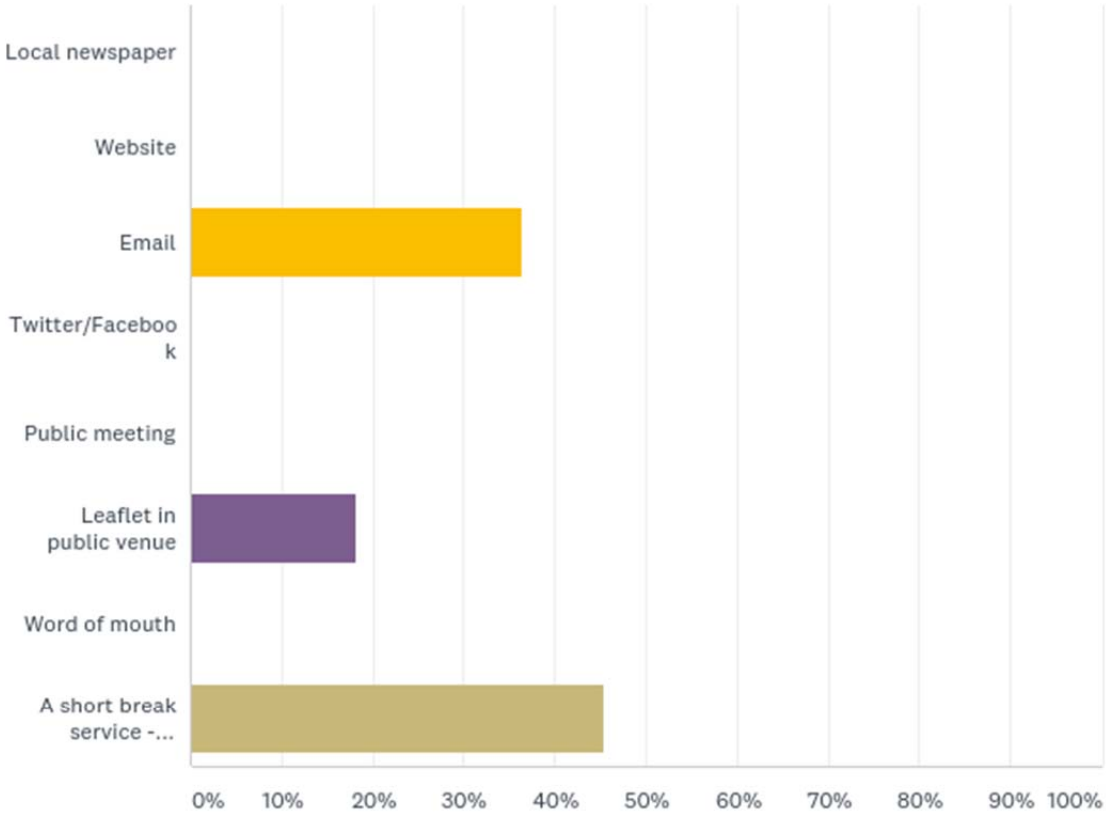
Answered: 13 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	61.54%	8
No	30.77%	4
Prefer not to say	7.69%	1
TOTAL		13

Q21: Where did you hear about this consultation?

Answered: 11 Skipped: 6



ANSWER CHOICES	RESPONSES	
Local newspaper	0.00%	0
Website	0.00%	0
Email	36.36%	4
Twitter/Facebook	0.00%	0
Public meeting	0.00%	0
Leaflet in public venue	18.18%	2
Word of mouth	0.00%	0
A short break service - please specify in the box below	45.45%	5
TOTAL		11

What do you think about the reasons we've given for why we need to make changes (in section 4 of the consultation document)?	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 of the consultation document). Please tell us why	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 of the consultation document)	Do you think introducing an allocation banding guideline for allocating short breaks would help make this clearer and fairer for all families? (Information on page 9 & 10 of the consultation document). Please tell us why	What do you think about the proposed banding system we have suggested on page 10 of the consultation document? Are there any changes you feel should be made to it if we adopt this approach for allocating short breaks?	Do you think the recommended service model will give families more choice and flexibility? (Information on page 12 of the consultation document). Please tell us why	Do you think one of the alternate models we looked at would be better than the one we have recommended? (Information on page 11 of the consultation document). If yes, please tell us why	Is there anything about the proposals that you feel would have a more positive or negative effect on you, and if so why?	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:
The real reason is to save money	It is so annoying going over the same info time and time again	Transition arrangements or prefably care up to the age of 25 should be taken in to account	Yes but I don't agree with your criteria hard working, married parents can need more support than single parents with good family support	Our respite allocation is very high but it is a life saver. I would love to have the help of a social worker. My package has never been reviewed in years!!	Only if there is a choice of services which I doubt for complex children		Negative if my respite allocation is reduced	I have some doesn't payments but, as an intelligent person, this is yet more work for me to do which I'd rather not have to do
reasons are clear and I would agree with need for fairness etc	not sure if this includes Helena team in 2011 we filled out lots of paperwork that went to CCG directly to allocate £. this is reviewed. a simpler process is welcomed and one that is more joined up	we recieve direct payments to fund carers, but other than that have no knowledge of what else is out there this would be very helpful	after reading it appears to only apply away from home. we have Helena team night carers. EVERYNIGHT. which is essential. i am not clear how this need is factored? ventilated child need 1:1 care 24 hours by someone	yes above. im coming to the open event to discuss face to face shortbreaks. its all very misleading. we have help primarily so we can have time off but so we can function day to day. we need two people at many points in the day. so most of the time we or school /TA work with Helena team. they are essential day to day care not short breaks, these have the way you make sure is different.	potentially yes. but there is also a risk that if it is disjointed have to navigate and with big ideas. im especially concerned for these with less of a voice to say what they need.	model 4 is good if it is well delivered	organising support care when you are stretched is an obsticle therefore the system must be easy, fast, responsive and deal with details well	i still dont understand fully when involved especially around allocations
some families may be eligible for respite but may never want to access it. I am concerned that our allocation may be reduced based on a potential increased demand. opening the unit on a Wednesday would increase capacity	agree in principle as there is a lot of repetition and time pressures on families, however, I am concerned about the robustness of the assessment process and sharing information between services.	need to be excellent links and good communication between agencies otherwise there is the room for error and for information to be over looked or misbehaved.	depends on the scoring system- theses bandings seem vague. very worried about a reduction in allocation and how this will be handled by services and families	see comment above	choice and flexibility and positive in principle however if this means a reduction in provision this may not be a priority for families		if our overnight respite is reduced this will reduced this will have a very negative effect on us. need to know more about personal health budgets and ease of commissioning a consistent service	qualified nurse led care at Ryegate house is invaluable. i know my child is in safe hands during stays there. staff have been responsive to my requests for certain nights and i therefore feel there is already a degree of flexibility
it is important to those that want and need it. get a fair allocation based on need - and that this is appropriate for each child and their needs so yes - reasons for change seem fair - am assuming those who need it and already and already get what is needed isn't compromised.	hard to say till it is tried but I would hope that yes it would be more straight forward	?	important to take in to account need and also social circumstances e.g family health, maybe other family help out but some have no family to help.	it reads ok on paper but depends what requirements are to meet low, medium, high, needs etc. depends on how this is marked which isn't explained here.	Sands - like we can choose where children access and where which is good.	possibly no not better but not sure. sometimes things are different to paper to in practice and so hard to say yet feel I would like more detail on criteria for 'low need', 'high need' categories etc.	not sure yet - feel my childs needs are high so feel shouldn't be affected negatively	
Fairness- I agree that the current system isn't fair and believe that the people who need and WANT the service should have access to it. I also agree that some people appear to get more than others even though needs may be exactly the same. Although people are entitled to the service not all want to access it. Access- I agree having one streamlined assessment would be easier and make more sense. It would also make it easier for new families to access services quicker not having to have individual assessment for different services. Flexibility- I disagree that the only way to give flexibility is to offer personal health budgets. This option is just giving us as Carer's more responsibility and something else to manage. The main reason we need short breaks in the first place is because we are busy and need time away from it all. I think that things like Helena team should be developed and managed in a way where people are actually getting shifts they want not just what they are being give because n one I talk to seems to get the shifts they need/want from them so something must be wrong. We can never plan what Restbite we have because it either gets cancelled by both	I agree that having one single assessment process would help as everyone would be getting judged against the same assessment. I think this assessment would have to be very broad spectrum to cover everything. If this assessment is going to assess me at needing less short breaks how is it helping me get the support I need? I think the level I am getting now is the level I need therefore I feel the current system is helping me to get what I really need.	Continuing care would have the children and families at the forefront of everything. I believe they would actually want what is best for them. However on the opposite end of the spectrum you have Sheffield city council who would only really care about the money involved in providing the care. A prime example of this is with the housing situation many Carer's living in council housing are having to make do with small bungalows that aren't fit for purpose because the councils attitude is 'its the best your going to get' do you really want to let continuing care be joined up with a service who has that attitude? You also have to remember every child is different with a different situation at home.	There is no detailed information on how you would be placed into these bands so find it hard to guess where we would fall. I am presuming it would be similar to the current continuing care assessment and be a point based system. If that is the case would one point higher or lower mean you receive more or less short breaks? The different levels are 'need for short break care' what makes you intitiled to 'medium need' level verses 'higher need' there needs to be way more information before anyone can form an opinion. Another example is these are stated as nights but what about the Helena team hours are these additional or part of you allocated nights? Looking at the information you have provided it's not looking promising on making anything clearer.	I think it could easily become unfair if points either way would give you more or less Restbite. Nights should mean nights and hours Restbite should be additional not included in allocated nights. I think the word 'need' isn't a good word to use. What I think I need is not what I will be assessed as needing. Is the level of disability taken into account with the banding system of is it purely based of family situation because from the examples you gave it was heavily based on family situation. I have family around me that support me but they all work full time and don't feel confident enough to do training required to be able to look after my daughter.	It's all well and good giving families these amount of 'nights'/ short breaks but you have put no thought into how the sevices will cope with what you say will be an increase in families needing the services. From what I see already using the services it is clear to see both Helena team and ryegate house are only just managing the children that they currently have. Also if you are going to allow flexabily how would it work for times like the school holidays and summer time which are going to be the most popular time to use their nights. How would this be managed? The example you used doesn't really suit people who have children who can't access things such as 'sensiry Play sessions' my daughter has nights at ryegate and these are like her social time where she gets to see other children and have time away from her mum and dad and have a good time.	I appreciate the situation is difficult but I am struggling to understand how services are going to cope with the increase without them in turn expanding to meet the demand. You clearly state people prefer the bed based provision that ryegate house provides but this has a limited space and there is not mention of expanding this. It was only a few weeks ago (8th March) when ryegate was forced to close because they couldn't get 1 nurse in the whole of Sheffield to cover the unit because the original nurse was sick. Is this an acceptable service that people should rely on? My main problem with the whole thing is that you have come to us once you have chosen your preferred model. You are not asking our opinion on what we think would work best. You are asking our opinion what we think to the model you have picked. Let's face it there's nothing anyone can say that is going to change anything.	I think one of the major negative effects on me will be if I get less Restbite because what we get at present works for us and has been a god send at times. It has allowed my daughter a social life and to also grow as a person and give her confidence with other people other than me.	You haven't come to us asking what model we'd like you have basically just come to us and said this is our chosen model what do you think about it. No matter what I or anyone else says you have already decided on your choice so what does our opinion really matter. You have given no thought to how the services will provide it. Personal health budgets may work for some people but they aren't for everyone. People who have children who are complex for example have a lot to do never mind managing staff, wages, sickness, tax and money. I think the model that has been chosen has potentin if executed correctly but it has also failed in many areas it terms of what is like in the real world. There is also hardly any mention of the Helena team and how the hours provided by them will work. It's already a badly managed service and I imagine this will only make it worse. Then there's ryegate house which is a brilliant device but is already strained how will it continue to provide the service?
Fair, easily accessible and flexible	its not a single assessment if it doesn't coordinate health and social care	parental preference how long the process takes from assessment to decision and how that can be speeded up in an emergency	yes but having a scale is a little confusing how do you differentiate between the upper and lower ends? I think it would work better as a maximum set amount with a percentage of extra for emergency care	answered above	choice yes, flexibility doesn't this depend on if the service can deliver it or have I got scope to use all my allowance in one place should I choose too?		reduced care is always a concern? what will it be replaced with and what are the processes if we cant? what support will be available. Again down to time frame from referral to receiving care/ a descision	nil
I agree that the use of funding needs to be more flexible and accessible to those who need it but are not currently accessing it.	Combining the assessment process can mean that you are offered support that you may not have applied for separately.		The banding process is much clearer and easier to understand. It will also help to correlate between nights allocated and funding available when using a PHB	I cannot think of any changes.	I think it provides flexibility for the varying needs of children.	All the other models are based on a 'one size fits all' approach which doesn't work. The needs of disabled children and their families vary dramatically and a flexible approach is best. Not all parents feel comfortable with bed-based care and not children like being away from home.	I think the new model and assessment process may open up this area if funding for us in the future as we are currently being assessed with continuing care.	I think the new approach is more flexible and easy to understand. It will help families in need of respite have more options on how to achieve this. It looks like it will also make the assessment process fairer, offering children on the lower end of the scale respite care without the need for expensive bed-based respite.

I like the idea of a streamlined approach to accessing services. The consultation is mainly cost-driven, which really worries families caring for disabled children.	Hopefully more straightforward	Hopefully reduce the lack of communication between services, but having been a special needs parent for 15 years, I shall not be holding my breath.It needs well thought out procedures, especially for emergencies. In my experience, that's where the system completely falls apart.	It depends on the bandings; if they exclude many children e.g. those with invisible disabilities, then no. I'm afraid I'm very cynical about this; it's more a cost reducing exercise than supporting families in need, like mine.	It suggests that just having one child with a disability is barely enough to access respite; you need to be a single parent parent, have own mental health issues etc. The overnight respite we access is our lifeline. Without it, we could be in crisis.	Personally I did not like the personal budget. It required paperwork for me & there were issues of having new PAs to train; it was barely worth the 'respite' gained.	If you've already decided that Model 1 & 3 aren't viable, we are limited to personal budgets or model 4 that you are wanting us to accept. Feels like a waste of time commenting!	I appreciate the big picture of budget restraints, but I am also fearful of how this proposal will play out for vulnerable families like mine.		
I agree the system needs to be fairer so everyone is given the same access to the available services.	We have been through many different assessments for different services which is time-consuming and confusing.	We need to have an established single point of contact so we know who to contact if we have any problems.	Every situation is different. It is good to have the bandings as a guideline but there may need to be flexibility.	I am concerned that we will end up with significantly less nights. At the moment we are struggling with what we have and are in the process of applying for more but this looks as if we will end up with less respite.	I think it is good to give options as different people will have different requirements depending on their circumstances. But this only works if there are the right services available to choose from and we know about them and how to access them.		As stated above, I am very concerned that we will end up with less respite when we feel we need more than the 75 nights we have now.	As above. Also, will Ryegate House continue to be closed on a Wednesday night? This makes it difficult to plan the occasional longer break.	
I agree with the reasons, much fairer process		I think considering if a child has an EHCP should be factored in. This is a huge document and has been verified by so many factors and such a long process that any child that has one should be easily accepted for the fund.	Could be risky been so black and white i.e. i don't quite fall into one banding, be mindful that there could be overlap and that needs to be factored in to any 'tick sheet' process.	as above for both questions 3 and 4.			no	I think as long as the variety is still there, i.e. breaks, clothes, pets, equipment etc.At the end of the day i always thik it's hard to put a price on making a child happy, anybody who thinks thay can do that is in the wrong job. Just be flexible in the approach, yes have criteria to measure but be flexible according to the needs of the child. For example autism is a hidden disability and its sometimes hard for people to see the work that goes into keeping the day running smoothly for that child even if they are high functioning. I hope by doing this process that parents comments are 'proposed' rather than just 'read' and filed onto a spreadsheet. Any panel chosen needs to be across all areas and everybody needs to be represented, not just representatives who look at financial or process elements, never forget the human factor...	
I agree with the need to make changes, we had no idea about this for years until a clinician asked us on a course about our sons condition.	Circumstances can change very fast and if the child is on a good day during the first assessment it can be wrongly decided.	can't think of any at this time	Our son is relatively stable at the moment but 3 months ago wasn't. We also have a daughter with a rare AI disease but we've never applied for any government funding for her. We've found over time that people think we're coping but don't realise we just put on a brave face. If you just go with who lives in the house, is the child stable at the time and how much support they have then some may fall through the cracks in the system.	You definitely need to take into account the family as a whole and not just the diagnosed child.			We've only had the grant twice but it has been used to the benefit of the whole family doing activities that our son has picked himself. As long as if we are able to access the grant it could continue to be used to benefit our son and family rather than being ring-fenced for something that he'd hate it will be ok.	I've no idea how the changes will affect us as we've only used the grant for the last 2 years and not asked for the full amount but just enough to pay for something that would be normally out of reach for our son. I wish we'd known about it when he was a lot younger.
this sounds like a fair system	This will need to be advertised in GP surgeries, children's centres, local authority premises and also pharmacies and hospitals in order to let families know of this funding.	There needs to be a shared system that each organisation can log onto to see the children's allowance, how many times they've had a break and when. The referral process needs to be clear and who can refer and where to refer to. It also needs to be clear that the referrer is not the one who makes the decision so that families don't become upset with individual workers.	As long as they understand why they are in the banding system and not be penalised if their child needs inpatient care. Inpatient care isn't a break when a child is ill due to parents visiting and time off work along with possibly other family circumstances and commitments etc	No it seems fair I think it should be clear to families that they have a prepaid 'wallet' that is used to debit funds for any breaks taken. These wallets are found on things like playstation and parent pay systems that school uses. A wallet is allocated money by the user and then can be used until a 0 balance. Similarly the CCG/NHS/Social Care could add to the wallet. It would be helpful for parents to see the cost for each debit made and how much is left.	If they can see the type of respite they can take. Perhaps in all levels some type of pre allocated sessions are set. For example, there are so many allocated play sessions, weekends, week day breaks etc. In lower levels perhaps play, weekend, overnight and day breaks allocated.	See above regarding pre-allocated session types	I'm a little concerned that as a Health Visitor we often see families who are struggling and unable to get support. There needs to be an easy way to refer or even self referral for all those able to do this themselves. Partnership working could help - children's centres helping families to refer or referring on their behalf. We have a lot of additional responsibilities and end up mopping up a lot of other services though we are not funded to do so or able to.	As health visitors we would like an easy referral process or single point of access for all users - families, professionals etc
It is good to make the system fairer and more equitable for families with disabled children to access services.	I would only have confidence however if the assessment was carried out by someone suitably qualified with a clinical role rather than someone who is interested in balancing the budget- in other words the assessment needs to be fair and needs based	Assessment process needs to be driven by the child's needs not by the system's needs	How the banding will be determined is not disclosed in this consultation- it needs to be fair and transparent and not driven by financial considerations.	I am concerned that you are setting an upper limit of 75 nights care based on the Looked after Child definition- it does seem this is being used to ration services and is not determined by the needs of the child.	It does not seem clear to me- if a child is allocated a particular banding can parents decide how to use those nights (eg Ryegate and/or Helena team) or will this be allocated and will the family only have a choice if they get a Personal Health Budget?	I think option 3 would be best as it will integrate Health and Social Care support- you have not chosen this as there is not enough money to do it but ultimately this is what the government will want.		I welcome the proposal to make provision fairer and allocation more transparent. I would want the new system to be easy to access in terms of referral in for assessment of need and I would want to receive feedback on the outcome of any referrals I make.
A poorly veiled attempt to hide the basic fact that you wish to reduce the current level of essential respite services.	The Helena Care team (previously the Ryegate Home Care team) assessment was a simple chat to discuss what the service could offer. The Ryegate House assessment was a simple chat at Ryegate after looking around the facilities they offered. Neither was strenous or difficult. We did not want or need to start overnight respite at the same time as the home care team started.	Despite having a profoundly disabled child with additional healthcare needs, they do not meet the requirement for Continuing Care. A joint process is liable to mean that yet again the children who can pass the continuing care assessment get a far better respite package than those who don't. We are tired of losing planned respite sessions at the last minute to those children who already get a far greater level of support than us.	It will be clearer that we are losing respite. Not sure how families will know it is fairer.	I'd be surprised if anyone looking after a disabled child/child with complex needs would needs so little respite in the lower bands or that parents would want to swap overnight care for support at an activity.	There isn't a suitable alternative to the services we already successfully access after a simple assessment process.	Model1 already works. Having a personal health budget doesn't magically change what services are available. The problems with cancelled respite sessions could be addressed by increasing current staffing levels.	A personal health budget forces parents to do another job in addition to their already heavy caring responsibilities as they now have extra work managing their child's budget to ensure they get the help they need without spending too much. We currently manage on the level of overnight respite, any reduction means that we probably would not and would be looking at a fulltime social services funded foster care placement.	They sound awful, no positives to be seen - just another reduction in provision.
Respite should be fair		Higher needs of my relative requires a different skill	Concerned that there will be a push to put people in lower bands. Does it get impacted by stays at bluebell	Low bands not enough nights			Yes lower nights and48 hour crisis cover not nearly enough	Unsettling need a good transition if expected to change	

Appendix E

Summary engagement feedback with families accessing NHS short-breaks provision (from February 2016 and August-November 2017).
Summary consultation feedback (March 2018)

- 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). **This was confirmed in the consultation although people were concerns about the delays this may cause in receiving support.**
- 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
- **All those who took part in the consultation (including families) agree to the a banding system would create a fair and clear allocation process**
- 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. **This was also echoed in the consultation. Whilst agreeing to a fairer banding allocation system the overall concern was if *they* (families) had a reduced offer**
- **Most respondents felt that the alternative models outlined in the consultation) would not be better than the preferred service model of overnight home- and bed-based and Personal Health Budgets**
- Most families would like choice on access rather than it being prescribed by the provider
- **Choice in providers was questioned by families – given the currently limited market for children with complex health needs**
- 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. **This was raised by some families who couldn't recall having a review/re-assessment**
- 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. **Consultation feedback has identified that families would welcome and emergency (responsive) offer**
- Reasons given for the need for NHS short-breaks was to improve sleep, send 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. **Families often refer to Direct Payments when PHBs are discussed. Concerns were raised over the management of Personal Health Budgets.**
- Disruption felt by some families about a night closure in August 2017 **(also mentioned in the consultation feedback), night closure in March 2018** 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.

<u>Things for further consideration</u>

There are some children who need respite and don't get or cant access it – raised by a staff member – tracheostomies.
TPN – not currently in scope of provision- feedback from one mum
PHBs useful for under 2s or Ryegate/Helena offering short blocks of time during the day – raised by one mum
Banding system talks about nights away from home – this may put some families off who would consider home respite
The local offer – private nurseries should be supported to take children with complex health needs
Any changes assessment should be linked to EHCP processes and transitional arrangements
Family factors – siblings and complexity of family set up have to be embedded in the assessment – raised by one mum
"When we finally embraced respite (Ryegate) it was lovely to explain my child's health needs without staff appearing phased by what he requires. I am so grateful for their (Ryegate) expertise".
Opportunity to buy additional nights from Ryegate House
Having a system that logs how much short-break care a child receives even if it exceeds 75 days
'Short breaks in its fullest sense are about the child's need to access breaks, holiday and activities that meet their needs too! Perhaps consider some of the children's groups' scouts, brownies holiday clubs – should count as respite too as part of social integration and inclusion'.
Capacity/limited resource of the Helen Nursing Team – mentioned throughout