



Derby City Council

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The Light House Residential Short Breaks Service - Update

Purpose

- 1.1 To provide an update on the current and proposed future arrangements of the Light House Residential Short Breaks Service following a period of public consultation between September and December 2019 as part of an on-going review of the service to ensure a delivery model that is future proofed and meets the need of young people and families who access the service. This report outlines the main findings from the consultation and next steps in regards to moving forward in relation to the service review.
- 1.2 The Integrated Disabled Childrens Service (IDCS), of which the residential short breaks service is an element, is jointly-funded between Derby City Council (DCC) and Derby and Derbyshire Clinical Commissioning Group (DDGGC), who contribute to a pooled budget held by the LA. The pooled budget pays for all the support from the Light House, including LA and health staffing. DCC manages the overall provision. DDCCG have a duty to meet the health needs of the children and young people.

Recommendations

- 2.1 To ensure CYP Scrutiny are aware of the key outcomes from the public consultation and proposed future direction of the service delivery model.
- 2.2 To note the financial and operational implications of the direction outlined in this report.

Reason(s)

- 3.1 The Light House Residential Short Breaks Service is a statutory service and is required to provide respite services to vulnerable groups of children, young people and their families across Derby.
- 3.2 Feedback from parents/carers from engagement sessions and public consultation has highlighted the need for the service – it is described as a 'lifeline' for maintaining disabled children within their families.

- 3.3 In addition, the provision of an effective short breaks service prevents disabled young people's family care breaking down, preventing the need for costly residential placements.

Supporting information

- 4.1 The residential short breaks service provide overnight breaks for disabled children based at the Lighthouse, which has 10 en-suite bedrooms, in 2 units (Sun and Star). The units have historically been run by a combination of nurses (currently provided by a specialist care provider – Nurture Care) and Residential Child Care Workers (DCC staff). The service is inspected by OFSTED and currently has a 'Good' rating, with the most recent inspection having taken place in July 2019.
- 4.2 Criteria for the service is for children aged 0-17 year olds with a diagnosed moderate-severe Learning Disability or any other life limiting illness. The service is used where parents are providing waking care and children have a very high level of personal care needs. Children stay 1-3 nights per month on average.
- 4.3 Sun unit is used for children with high level multi health needs and Star for children with Autistic Spectrum Disorder (ASD) and behaviour that is difficult to manage.
- 4.4 As highlighted earlier, the residential short breaks service is presently undergoing a service review to look at future models of operational delivery that are sustainable, can promote a high quality experience for young people accessing the provision and works within the given budget envelope.
- 4.5 Unlike a number of other residential short breaks services across the region, the Light House is unusual in that it meets the needs of all children and young people, including those with the most complex health needs. Until May 2019, care was provided by a multi-disciplinary team of Residential Child Care Workers employed by Derby City Council and nursing staff employed by an NHS health provider.
- 4.6 The contract with the healthcare provider ended on the 31st May 2019 after the provider gave notice. Interim arrangements were then put in place. This provided an opportunity to look at future models of operational delivery and provided an opportunity to align service delivery with other residential short breaks services, whereby Social Care staff deliver a range of appropriate health tasks based on national guidance.

Interim Model.

- 4.7 Part of the interim model work involved up-skilling DCC staff (Residential Child Care Workers) to adopt health tasks that were once delivered by nursing staff (where appropriate), with the potential for DCC staff to deliver a Social Care led model moving forward (dependent upon the outcome of the

aforementioned consultation). DCC staff were consulted on changes to their roles to allow for this up-skilling between April and June 2019, which was successfully completed and paved the way for roll out of the interim model. An Equality Impact Assessment was completed as part of the review process to ensure there was no negative impact on young people accessing the service as a result of the proposed model.

4.8 The priorities for the interim arrangements was to:

- provide some direct nursing care to ensure continuity of service provision and safety
- move towards a stronger Social Care led model, whilst ensuring that appropriate healthcare needs were safely met, i.e. starting to upskill Social Care staff in delivering health interventions with training, competency assessing and governance development
- Recruit Social Care staff in line with the revised structure
- Ensure the new Social Care infrastructure and governance is robust
- Continue to listen and learn from parents, carers and staff on what works well and what needs to change

4.9 Continuity of service delivery was maintained during the transition between health care providers and during the interim arrangements. However, since April 2019 the Light House has been able to safely open 3 nights per week, when qualified nurses are on duty, which has meant a reduced offer for families. This has been due to delays in recruiting to the full Social Care staffing establishment and subsequent delays in upskilling and competency assessing Social Care staff in appropriate health tasks. Attracting high quality staff has been challenging but as of February 2020, we have recruited to almost all of the necessary Social Care staff required run the service effectively.

4.10 Social Care staff are enjoying new roles and responsibilities with the right support. Supervision and feedback from trainers is positive. The development of a framework for Social Care staff to deliver appropriate health tasks under Local Authority governance has been completed and was approved at both DMT and Health and Safety Committee in December 2019. Work will remain on-going in regards to ensuring a robust governance and accountabilities framework going forward between DCC and Derby and DDCCG.

4.11 As we now have a robust model in place, a sufficient number of Social Care staff recruited, with a number having been trained and competency assessed and other Social Care staff in that process, the number of nights offered to families can be extended; with a plan to move to four nights a week at the end of February 2020 and potentially five nights a week in March 2020.

4.12 The interim period was initially planned to run up until January 2020. However, delays in recruiting DCC Social Care staff and the subsequent delay in training and competency assessing this group of staff meant that DCC, DDCCG and Nurture Care agreed to extend the interim model until April 2020, continuing

the model on the same basis as for the prior seven months. This was affordable within the budget envelope and allowed time to reflect on the outcomes of the public consultation and take the proposals arising from this through the various governance processes in both the DDCCG and DCC.

- 4.13 On 31.1.20 the Light House successfully ran its first Social Care led night with no health practitioners. This was a confidence boosting achievement for both DCC staff and practitioners.
- 4.14 The only matter outstanding in relation to the interim model is with regards to four families who have children with higher level health needs that are unlikely to be able to be met by Social Care staff (even with the on-going training).
- 4.15 In order to assess how these children's needs can best be met, multi-disciplinary panels are planned between Health and Social Care professionals (along with families). These panels have commenced and there are potential options to have a model where care follows the child through highly trained Health Care staff (who already know and support the child in other environments) coming to the residential short breaks unit with the child and the potential for nursing intervention (where this is assessed as needed) as part of this package of care.
- 4.16 However given the small number of families this effects, there is little impact on the broader group of children and families accessing the service whose needs can safely be met by DCC Social care staff in a more holistic model of care delivery.

Engagement and Consultation.

- 4.17 A programme of intensive pre-engagement was launched on 19th November 2018 followed by a formal, 90 day consultation from 5 September 2019 to 3 December 2019 which was run alongside the interim model.
- 4.18 Following an evaluation of the pre-engagement programme, the joint project team of DCC, NHS Derby and DDCCG recommended that a single option, jointly-delivered consultation would be appropriate on the basis that:
- The intensive procurement programme demonstrated there was no suitable provider available to deliver all the key elements of the previous model within the timescale required.
 - To “do nothing” following the provider serving notice would have meant that the service could no longer continue and as the Light House is a statutory service, this was not an option.
- 4.19 The draft consultation document was submitted to the governance processes of DCC, NHS Derby and DDCCG, requesting permission to co-consult. The consultation questions are attached as appendix 1.

- 4.20 Direct targeting of parents/carers, partners/stakeholders, networks and others formed the core of the consultation programme and the groups in the table at appendix 2 were directly targeted at launch and repeated again during the consultation phase. 19 responses were received during 3 month consultation period. 10 of these were parent/carers.
- 4.21 Other promotional channels for the consultation included: the Light House consultation being listed on the DDCCG website, including the survey link, along with the relevant information. Derby City Council also had a page on their main website where the survey link was listed.
- 4.22 For the duration of the consultation a total of 816 people visited the pages.
- 4.23 Facebook was also used and based upon information and advice from parents and carers we were also able to reach groups which would otherwise have been closed to us and the consultation information and survey link was shared to the following:
- SEND Parents 4 Change (Closed group)
 - Living With Special Needs Today (Closed group)
 - Cartoon Heroes (Closed Group)
 - Tegan's Butterflies (Closed Group)

Regular tweets were issued via the DDCCG and DCC Twitter accounts.

- 4.24 The table attached at appendix three highlights the themes from the responses received in the consultation. The table focuses on ensuring that comments and concerns are addressed along with potential solutions.

Key Themes from Consultation feedback.

- 4.25 53% of respondents were currently accessing the residential short breaks service.
- 4.26 There was positive feedback on elements of the Lighthouse that respondents felt worked well, such as: Staff continuity provides routine and stability, High quality care, Regular care reviews are good, Good communication, Staff listen and are patient with my child.
- 4.27 In regards to improvements that respondents felt were needed, this included: returning to a full allocation of nights, more time for children to develop social and independent skills, a larger allocation of nights and children with more complex needs requiring more flexible respite as they become unwell more often.

- 4.28 In relation to aspects missing, comments included: less continuity of care than usual (interim), a more holistic view and response of the child's wider needs, assurance that staff are properly trained and know how to problem solve in e.g. first aid, epilepsy.
- 4.29 59.7% of all respondents were either neutral, or above of which 24% agreed or strongly agreed with the proposed model.
- 4.30 In regards to those who did not agree with the proposed model, themes were: who will be providing the specialist care the children with complex health needs require, who will provide the update training on a yearly basis.
- 4.31 Where respondents felt that the changes (proposed) would have a big impact, comments included: for carers to know the child is important, having the right support and supervision and training in place for staff, trusting staff.
- 4.32 There were a range of response in regards to which days, nights of the week worked best for respondents and this is something that will need to be managed operationally based on staffing rotas in conjunction with families' individual views and needs.
- 4.33 In relation to how we could support families more in a crisis, responses included: more flexibility and access to the service at short notice in case of any crisis, emergency bed available.
- 4.34 There was little appetite demonstrated around attending social interaction events at the Lighthouse by respondents.
- 4.35 On the basis of the feedback and the responses that are outlined in the table located at appendix three, DDCCG and DCC recommend that the proposed model of delivery for the Light House is approved and implemented.
- 4.36 The table below summarises the old and proposed model and potential benefits on outcomes for children from new arrangements.

The Light House (Derby) Residential Short Breaks Services for Children and Young People with Disabilities December 2019			
Date	Staffing model for 48 children (current)		Outcomes for children
Old Until 31 May 2019	Care and social needs met by care staff	Health needs met by nurses	Multiple carers Restricted social experience Increasing service cancellation

Interim 1 June 2019 to 31 March 2020	Care and social needs met by care staff	Health needs met by nurses	Reduced service availability Increasing continuity of carer
	Training for care staff to meet some health needs with supervised practice		
Proposed model after consultation From 1 April 2020	All care, social and health needs met by social care staff trained in child specific interventions trained and supervised by nurses- 44 children	Bespoke packages of care for children with most complex health needs 4 children	Better continuity of carer Better quality of social experience Improved flexibility and increased availability of service

4.37 The new service would mean:

- Better continuity of care for the majority of children and young people, as all aspects of their care will be delivered by their main carer (instead of a split between nurse and Social Care staff as previously); for those with higher health related needs there will be tailored specialist support
- Children with the most complex needs will still benefit from mixing with other children.
- Consistency of service provision with appropriate levels of staffing that will mean all staff shifts will be covered, eliminating or significantly reducing the need for short notice cancellations.
- A sustainable model that will help to ensure the continued operation of the residential short breaks service in the future.
- A service that parents and carers are confident in and are reassured that care is safe.

4.38 A Social Care led model for the majority of children using the Light House can viably and safely meet need and enable children to have a more fulfilling social experience.

This would be delivered in conjunction with:

- Governance within Ofsted/CQC guidance
- Robust care plans with clear emergency plans
- Health training with child specific competency assessments, supervision and access to health advice through a CQC registered provider

Principles of a long term model for children with the most complex health needs/cohort:

- Known carers/continuity of care/r will provide consistent and best quality care
- Care that is safe
- Care model is agreed for each child on an individual basis through a professional peer review panel taking into account clinical information, care plans and parents carer views
- Appropriate governance in place

Next Steps

4.39 A post consultation and proposal report has been completed by DDCCG and approved by:

- CCG Engagement Committee on 8.1.2020
- ISC County Overview and Scrutiny on 20.1.2020
- CCG CLCC for clinical sign off on 24.1.2020
- CCG governing body on 6.2.2020.

We are now in a position to move forward with the implementation of the proposed model with key activity being:

- Continuation of Social Care staff training and competency assessing.
- Assessing the needs of the high health needs cohort.
- Procuring the on-going training and competency assessing required for Social Care staff.
- Safely increasing the number of nights the residential short breaks service offers a service per week.

Other options

5.1 Other options that have previously been considered include:

- Recommission health support on like-for-like basis. Providers approached were not able to accommodate this and operational difficulties would have made this an unviable option.
- Personal budgets.
- Use of other respite facilities – for example, Caudwell House, Crocus Fields, Rainbows/Bluebell Wood hospice.
- Separate provision for higher needs young people.
- Full delivery of the service by an alternative provider.

5.2 The content of this report clearly outlines how the proposed model offers a superior quality of service to the alternative options that had been identified at an earlier point in time.

Financial and Value for Money issues.

- 6.1 The current pooled budget for the Light House, including residential and community services, is £2,408,359 per annum. This is a contribution of £1,397,025 from DCC and £1,011,334 from the DDCCG. This budget covers a range of provision at the Light House, with £1,093,653 per annum covering the current staffing for the Residential Short Breaks unit.
- 6.2 The estimated costs for delivering the service over 2019-20, incorporating the interim model, which will have run for a ten month period; based on a 5 night opening per week basis requires further work to ensure all nursing cost to date are factored into the budget line, however the financial forecast for this financial year is in line with the available budget. This includes costs of:
All LA staff working at the unit, including another layer in the structure (i.e. RCCW Level 3), LA staff undertaking additional responsibilities; with an accompanying increase in salary due to salary grade uplifts and increased LA staffing numbers to accommodate the reduction in health staff numbers.
- 6.3 Nurses from the Specialist Care provider delivering 75 hours of coverage per week to children and young people with medium and high levels of health care needs, which tapered off as more Social Care staff were recruited, trained and competency assessed (to deliver health tasks).
The costs of training for LA staff to cover health interventions that would meet the needs of 44/48 children and young people currently accessing the unit in the interim period and potentially as part of a longer term model.
- 6.4 Competency assessing that would need to follow training in order to ensure that LA staff are formally approved to carry out safe health interventions. This is required on a child by child basis.
- 6.5 Training costs will reduce going forward, as the bulk of training has been required in the interim period.
- 6.6 The costs for the model moving forward will depend on the outcomes of the multi-disciplinary panels that are taking place for the four high health needs young people, as this will assess needs, how these can be met and the potential costs of this care. Work is on-going in this regard with the DCC Finance Service, who attend Section 75 meetings with both LA operational staff from the IDCS and DDCCG staff involved in this area of work.

Legal implications

7.1 The service has a statutory basis for delivery under the Children Act 1989.

Other significant implications

8.1 The service is in a confident position to move the proposals forward in conjunction with DDCCG. Approvals have been given and there will be a communication planned for parents/carers/key partner agencies/stakeholders following CYP Scrutiny Review Board on 24.2.20.

This report has been approved by the following people:

Role	Name	Date of sign-off
Legal	Olu Idowu	12.2.20
Finance	Alison Parkin	11.2.20
Service Director(s)	Suanne Lim	13.02.20
Report sponsor	Suanne Lim	
Other(s)		

Background papers:

List of appendices:

Appendix 1 – list of consultation questions

Appendix 2 - Groups Consulted with

Appendix 3 – Consultation responses and proposed solutions table

Appendix 1 - consultation questions

The Public Consultation survey contained 15 questions as follows:

Q1 Do you or your child currently access the Light House residential short break services?

Q2 Are there any parts of the Light House residential services that you think work really well?

Q3 Are there any parts of the Light House residential services that could be better for you?

Q4 Are there any aspects that you feel are missing at the Light House? (please list in order of importance).

Q5 Having reviewed our initial proposed service model please tell us the extent to which you agree or disagree with the proposal. (0 strongly disagree and 5 agree)

Q6 If you do not agree with the proposed model please tell us which bits you are concerned about in the space below.

Q7 Please tell us the impact that the proposed changes would have on you, your child or your family (0 low impact 5 high impact)

Q8 If you have answered that the changes will have a big impact, please tell us what you think the main impact will be in the space below. *Please see table below*

Q9. If you had the opportunity to choose your days of the week for overnight respite, which nights would work best for you? Please tick all that apply.

Q10 Some families need a break at short notice or due to a crisis. How do you think the Light House residential short break services could support parents and carers who need a service in a crisis?

Q11 Some parents and carers have told us that they would like the chance to combine their allocation of nights to have longer breaks for example during school holidays. What type of support is most important to you?

Q12 Would you attend regular social meetings such as coffee mornings at the Light House?

Q13 Do you feel you would like more information on other services such as Community Support Teams (CST) or link care?

Q14 Do you feel you would like more information on other services such as Community Support Teams (CST) or link care?

Q15 Do you have any other comments?

Appendix 2.

Groups directly targeted at launch and repeated again during the consultation phase.

Recipient	Channel
Parents/carers of Derby City children	Letter, email and phone
Parents/carers of Derbyshire children	Letter, email and phone
Parents and carers of children on waiting list	Letter and email
Senior leads and staff at relevant departments for DC and DCC	Email from project leads
Umbrella	Email request to share with networks
Social workers	Targeted to specific workers
Funability	Group presentation
St James Centre	Request to share with networks
Parent Carers Forum	Requested to share and promote
Healthwatch Derby City	Requested to share and promote
Stakeholders, MPs etc.	Via bulletins and updates
Healthwatch Derbyshire	Requested to share and promote
Derby City Childrens and Young People's Scrutiny Panel	Request to share with panel and councillors
Derbyshire County Council Improvement and Scrutiny Panel	Request to share with panel and councillors
Parent Carers	Requested to share and promote
SEND Parents 4 Change	Requested to share and promote
Living With Special Needs Today	Requested to share and promote
Disability Equality Hub	
Cartoon Heroes	Requested to share and promote
Tegan's Butterflies	Requested to share and promote
Komplex Kidz	Requested to share and promote

Appendix 3.

The table below highlights the themes from the responses received.

As the consultation is based upon a single option it is essential that the feedback both positive and negative is incorporated into the final proposal for the new model.

The table focuses on ensuring that comments and concerns are addressed along with potential solutions:

Feedback from the public consultation	Responses by commissioners plus potential solutions and other comments
Families who have a child at the Light House	
<p>Q1 Do you or your child currently access the Light House residential short break services?</p> <p><i>Answer: Yes: 47% No: 53%</i></p>	<p>We need to understand the differences between feedback from parents and carers and that from staff and other partners and stakeholders. Feedback specific to other responders/stakeholders who are not parents and carers is included at the end of this table.</p>
<p>Q2 What works really well at the Light House?</p> <p>Themes are:</p> <ul style="list-style-type: none"> • Excellent service works well • Reduces family breakdown • Staff continuity provides routine and stability • Helps children feel safe • Reassuring to parents and carers. • High quality care • Attention to detail important • Regular care reviews are good • Good communication • Staff listen and are patient with my child • Written diaries about stays are helpful 	<p>We believe that the proposed model fully reflects the aspects that parents and carers consider work well and our intention is to build upon these strengths if the model is approved</p>
Q3 Are there any parts of the Light House	The service has a defined budget envelope and

<p>residential services that could be better for you?</p> <p>Themes are:</p> <ul style="list-style-type: none"> • To return to full allocation of nights • More time for children to develop social and independent skills • A bigger allocation of nights • More funding for the Light House in all departments • Better management • Children with more complex needs, require more flexible respite as they become unwell more often 	<p>running a safe, high quality service has been the priority as the interim model has developed and pending the outcome of the consultation process.</p> <p>Recruiting staff of the highest calibre and experience to ensure that the expectations described in Q1 responses above has resulted in a short term reduction to three nights as the recruitment process took longer than expected.</p> <p>If the proposed model is approved the service will be able to move to a full staffing position by April 2020. As a result the number of available overnight stays can increase and flexibility can be considered.</p>
<p>Q4 Are there any aspects that you feel are missing at the Light House?</p> <p>Themes are:</p> <ul style="list-style-type: none"> • Less continuity of care than usual (interim) • More input/staff training in non-medical areas i.e. social interaction, communication, emotional wellbeing • A more holistic view and response of the child's wider needs • Assurance that staff are properly trained and know how to problem solve in e.g. first aid, epilepsy 	<p>Continuity has been more limited in the interim due to staff changes. Once all staff are recruited this will improve. Each child continues to have a key worker.</p> <p>The opportunity to test out training care staff to deliver some health related tasks within national guidance has had a positive response from care staff and has raised no concerns from parents and carers. This means social care staff would be able to provide all of the health and social care and social activities for most of the children.</p> <p>Social care staff training on health issues is currently and in the future would be delivered by registered qualified nurses through face to face sessions with workbooks. Competency assessments are child specific.</p>
<p>Q5 Having reviewed our initial proposed service model please tell us the extent to which you agree or disagree with the proposal.</p> <p><i>Answer: 59.7% of all respondents were either neutral, or above of which 24% agreed or strongly agreed with the proposed model</i></p> <p><i>To note</i></p> <p><i>The direct engagement sessions with parents and carers indicated that parents and carers had a positive experience of the interim model of care except that they</i></p>	<p>Childrens needs are assessed individually and managed through the child's Light House Care Plan – this includes all the care/emergency plans from all the professionals and are signed off by parents and carers to ensure care is safe</p> <p>Specialist packages of support for children with more complex/unstable would be agreed on an individual basis.</p> <p>Social care staff would not take on medical tasks they are not competent or safe to deliver.</p> <p>Under OFSTED and CQC guidance social care</p>

<p>would have liked a return to more nights. The concerns when expressed were around clinical assurance as is Q6 below.</p>	<p>staff can take on some additional roles and responsibilities if they are trained, regularly supervised, assessed as competent and the right governance is in place. These include</p> <ul style="list-style-type: none"> • Oral and topical medication administration • Epilepsy awareness and emergency treatments • Enteral feeding (via gastrostomy) tubes • Medication administration e.g. via enteral (gastrostomy) tubes
<p>Q6 If you do not agree with the proposed model please tell us which bits you are concerned about in the space below</p> <p>Themes are:</p> <ul style="list-style-type: none"> • Who will be providing the specialist care the children with complex health needs require? • Who will provide the update training on a yearly basis? • Identifying issues quickly and responding takes years of experience • This is the only option we have to work with. We need to make it work 	<p>Children with more complex/unstable, specialist packages of support would be agreed on an individual basis (see Q8 response)</p> <p>If the proposed model is approved, ongoing training assessment, supervision and advice for all Light House staff would be provided by trained nurses employed by a CQC registered provider.</p> <p>Social care staff would not take on medical tasks they are not competent or safe to deliver</p> <p>Social care staff have known the group of children attending the Light House for a number of years and have got to know them and their needs very well.</p> <p>The clinical arrangements have been scrutinised by the CCG nursing and quality team to ensure governance is appropriate and robust.</p>
<p>Q7 Please tell us the impact that the proposed changes would have on you, your child or your family</p> <p><i>Answer – 60% reported a neutral, or higher impact of which 53% were high or very high impact</i></p>	
<p>Q8 If you have answered that the changes will have a big impact, please tell us what you think the main impact will be in the space below.</p> <p>Themes for parents and carers are:</p> <ul style="list-style-type: none"> • For carers to know the child is 	<p>The Light House is for children who are well and stable. If a child becomes unwell during their stay the care plan should be followed and parents/carers informed.</p> <p>All staff are trained in a range of core skills including recognising the unwell child and managing epilepsy</p>

<p>important</p> <ul style="list-style-type: none"> • Having the right support and supervision and training in place for staff • Trusting staff • Access to nurse advice for social care would be helpful • Having the right support and supervision and training in place for staff 	<p>If the proposed model is approved ongoing training assessment, supervision and advice for all Light House staff would be provided by trained nurses employed by a CQC registered provider.</p> <p>In the proposed model children with more complex/unstable needs would have specialist care packages developed on an individual basis through a professional review panel that involves parent and carer views so that care is safe.</p> <p>Future procurement arrangements for health needs that cannot be met by the Light House staff that know them will fully take into account appropriate clinical guidance and requirements. The learning from the interim model and the bespoke approach to children with the most complex needs will enable us to provide a safe service that reflects individual needs.</p>
<p>Q9. If you had the opportunity to choose your days of the week for overnight respite, which nights would work best for you?</p> <p>Themes are:</p> <ul style="list-style-type: none"> • Day time respite only • Light House to be open more nights in the week • Full weekend break - Friday afternoon to Monday morning • More notice to be able to plan more in advance • More breaks and trips in school holidays 	<p>It is recognised that family's needs are very individual and specific to their circumstances and the broad range in the requests for flexibility reflect this.</p> <p>The proposed financial envelope limits the availability of extended nights of operation.</p> <p>With full staffing levels in the new service, it is believed that it would be unrealistic to commit to the complete flexibility desired. However the proposed model offers greater capacity and therefore flexibility than previous arrangements where the lack of flexibility and short notice cancellations was a source of concern and distress for parents.</p> <p>If the proposed model is approved it is reasonable to assume that a level of these requests will be achievable. Light House staff are planning to consult each parent and carer on their family and child's individual circumstances to understand what is most important to them and to try and provide greater choice within staffing capacity.</p>
<p>Q10 Some families need a break at short notice or due to a crisis. How do you think the Light House residential short break services could support parents and carers</p>	<p>The Light House is not registered with OFSTED to provide crisis care to children not known to them.</p> <p>As described in Q9 above, the proposed new</p>

<p>who need a service in a crisis</p> <p>Themes are:</p> <ul style="list-style-type: none"> • More flexibility and access to the service at short notice in case of any crisis. • Emergency bed available • Provide a similar crisis model to Rainbows Hospice where there is a clear 'crisis' criteria 	<p>arrangements will allow some flexibility to meet needs in of an urgent nature on an individual basis.</p> <p>The proposed service does not create a solution for crisis care.</p> <p>Social care to consider options such as keeping a bed aside for emergencies if rostering staffing allowed and explore how other providers support families in crisis. Keeping a 'crisis' bed free may reduce beds on a night by night basis</p> <p>The service could explore more formally whether there is an option around short notice beds due to sickness of other children accessing the service.</p>
<p>Q11 Some parents and carers have told us that they would like the chance to combine their allocation of nights to have longer breaks for example during school holidays. What type of support is most important to you?</p> <p>Themes are:</p> <ul style="list-style-type: none"> • Opportunity to 'bank' some nights to have longer breaks occasionally (i.e. 4-6 nights in a row) • Families of children with very complex needs would benefit from longer breaks as they do not have much time left once dropped off with all their equipment before child needs collecting again. • Takes a long time for families to wind down when providing intense care. • End of life care maybe requested by families 	<p>It is recognised that family's needs are very individual and specific to their circumstances. The broad range in the requests for flexibility reflects this.</p> <p>It would be unrealistic to commit to the level of flexibility requested. However the proposed model offers greater capacity and therefore flexibility than previous arrangements where the lack of flexibility and short notice cancellations was a source of concern and distress for parents.</p> <p>The Light House residential short breaks service is not registered for end of life care. Support is provided but it is not intended to be an end of life health service.</p>
<p>Q12 Would you attend regular social meetings such as coffee mornings at the Light House?</p> <p><i>Answer Yes – 12.5% No or don't know – 87.5%</i></p> <p>No narrative in the responses</p>	<p>If the proposed model is successful it is hoped that a community of interest for parents would be developed</p> <p>We would be happy to explore developing a less intrusive approach to communication with families and carers such as a newsletter, as we appreciate how busy life is</p>
<p>Q13 Some parents and carers have told us that school holidays can be particularly</p>	

<p>difficult. Is there anything else you would like us to consider to support you with this?</p> <p>Themes are:</p> <p>No narrative in the responses</p>	
<p>Q14 Do you feel you would like more information on other services such as Community Support Teams (CST) or link care?</p> <p>Answer – Yes - 47% No – 57%</p>	<p>The response reflects the 2 groups that responded.</p> <p>The social care team based in the non-residential section of the Light house will be able to provide more information on community support for parents and carers e.g. Umbrella, Progress Care and Funability</p>
<p>Q15 Do you have any other comments?</p> <p>No narrative in the responses</p>	
<p>Other responders/stakeholders who are not parents and carers</p> <p>Theme are :</p> <ul style="list-style-type: none"> • Respite reduces families breakdown • Consider daytime respite options • Concerns raised regarding children with complex needs <ul style="list-style-type: none"> ○ social care should not be responsible for their care ○ a registered nurse is needed on site as these children can become unwell quickly and nurses are needed to provide medical assistance in an emergency ○ nurses are needed to assist, train, supervise care staff ○ nurses would provide reassurance to parents • Improved communication between the (Light House) with the KITE team needed • Safe decision making is essential • Consider using continuing care team to support families to access the Light House 	<p>Social care staff will only take on responsibilities within their scope of practice and within the parameters of national guidance from RCN, OFSTED, and CQC and in line with most models of residential short breaks delivery across the region.</p> <p>All social care staff are trained in a range of core skills including recognising the unwell child and managing epilepsy. Training will be updated alongside competency testing to ensure a safe and high quality delivery of services.</p> <p>The Light House is for children who are well and stable. If a child becomes unwell during their stay the care plan that includes emergency plans should be followed and parents/carers informed.</p> <p>In the proposed model children with more complex/unstable needs would have specialist care packages developed on an individual basis through a professional review panel that involves parent and carer views so that care is safe.</p> <p>The nursing and quality team in the CCG have reviewed the interim arrangements and will fully review any long term model to ensure effective governance and safe care.</p>

