



Public Consultation Report On The Light House (Derby) Residential Short Breaks Services for Children and Young People with Disabilities

31 December 2019

**This consultation was co-delivered by NHS
Derby and Derbyshire Clinical Commissioning
Group and Derby City Council**

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Introduction and background

The Light House is an Integrated Disabled Children's Service that is jointly funded by Derby City Council (DCC) and the NHS Derby and Derbyshire Clinical Commissioning Group (CCG) and was set up in 2004. Within the Light House there is a residential short breaks service that provides regular overnight breaks for children and young people from 0 to 17 years of age with a wide range of disabilities from autism and/or challenging behaviour to complex physical health needs. The residential unit is a purpose built environment with 10 en-suite bedrooms divided into two units, 'Sun' and 'Star' with one focussing on children with physical health needs and the other on children with challenging behaviour. Some children have both sets of needs. Parents and carers have told us that this service is of significant importance to them and that it makes a huge difference to the quality of their family lives.

The eligibility criteria for the service specify that children must be aged 0-17 years 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 2-5 nights per month on average. Most children using the residential short breaks service are from Derby City. A very small number of children with the most complex physical health needs come from Derbyshire as their health needs cannot be met by Derbyshire County Council's own respite provision.

Staffing ratios in the two units depend on individual risk assessments and are tailored based on need:

Star Unit

This is a 4 bed unit for children and young people with behaviour that is difficult to manage. A high proportion have a diagnosis of Autistic Spectrum Disorder (ASD). Staffing ratios vary and can be up to 3 staff for 4 young people at any one time.

Sun Unit

This has 6 beds and is for children with multiple disabilities, complex medical needs and physical impairments. Some children and young people also have behaviour that is difficult to manage and/or have a diagnosis of ASD. Others have moving/handling needs which require one to one support. A small number of children and young people with a higher level of health need may require one to one care - of these most will have continuing health care packages.

The ethos of the Light House (Statement of purpose 2018)

'The centre offers short breaks to young people so they can enjoy and achieve in a homely environment, giving parents/carers a break. The centre promotes play and stimulation with appropriate peer and friendship groups. All young people are assessed for the appropriate groups so they are safe and happy. Planning is paramount in addition to risk assessment of peer groups.'

Parents and carers view the Light House as a vital lifeline as described in the following comment from a parent which is consistent with the feedback throughout:

"My child loves to come to the Light House, where he feels secure, happy and knows the staff that look after him. We feel happy that he is having high quality care and this has continued throughout the difficult transition period the staff have had to go through. He enjoys the opportunities to go outside (in the garden, or on little trips out when weather and staffing allow), has plenty of space indoors to walk around and opportunities to have his sensory needs met."

Unlike most services of this nature the Light House residential short breaks service 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 for residents was provided by residential child care workers employed by Derby City Council and nurses employed by a local NHS provider. The contract with the local health care provider ended on the 31 May 2019 after the provider gave notice to stop providing the service. This allowed commissioners to start to review the service alongside other similar residential short breaks services (where social care staff deliver a range of appropriate health care tasks based on national guidance), as there had not been a full service review since 2004.

Commissioning arrangements

Derby City Council has a responsibility to ensure short breaks are provided for children and young people with special education needs and disability (Children and Families Act 2014). NHS Derby and Derbyshire Clinical Commissioning Group is responsible for meeting the health needs of the children and young people using these services.

The Light House is jointly commissioned by Derby City Council and NHS Derby and Derbyshire Clinical Commissioning Group (CCG). Part of the service is funded through Section 75 of the Health and Social Care Act 2012. This enables local authorities and NHS bodies to pool resources and delegate certain functions to other

partners where there is shared responsibility. Derby City Council is the lead organisation for the Section 75 arrangements, though decisions are made jointly.

The Light House residential short breaks review was jointly led and managed by the City Council and CCG teams. It was managed through a project planning process within existing Section 75 structures, where decision making and assurances were jointly made and 'signed off' through both City Council and CCG governance routes as appropriate. This ensured robust and safe decision making and provided shared ownership, knowledge, skills and rigour.

Changes to the service

The Light House has been open since 2004 and there has never been a service review, to see how the health and care needs of the children and young people using the service are met.

The original service model was provided by a nursing team from local NHS provider and a team of residential children's care workers employed by Derby City Council. All clinical tasks were undertaken by nursing staff and all other care was provided by City Council staff. This meant that if a child had any health care need, however big or small, they would need to have the support of a nurse during their stay. This sometimes prevented children going out on trips, as the nurses were based in the unit.

Having two teams with different roles meant there was limited flexibility to provide cover for staff absences. This was more likely to lead to short notice cancellations of stays, making the service less reliable for families.

At the end of 2018 the health care provider gave notice of their intention to stop delivering services at the residential short breaks unit and ended their contract at the end of May 2019. The immediate priority for commissioners in the City Council and the CCG once the health care provider had given notice was to ensure continuity of service provision for families from the 1 June 2019.

Whilst the City Council care staff remained the same, it was jointly agreed in the short term to continue with the same delivery model with an alternative health provider delivering health care tasks and council staff delivering all other elements of care for safety reasons. This allowed the opportunity for an interim period to safely test new models. It also allowed time to review the service, explore longer term options and consider Care Quality Commission (CQC) and Ofsted guidance that allows for more flexible care delivery.

Following due process, after testing the market and engagement with families, children's commissioners in the City Council and CCG jointly developed a service specification for a new health care provider. Procurement was through the CCG following NHS regulations (see procurement section). This was informed by an

Equality and Quality Impact Assessment (EQIA) which is a critical part of the change process for any CCG commissioned service and the Light House EQIA was presented to the CCG EQIA Panel to provide assurance and it established that:

- The physical condition and age of some of the children who use the Light House has meant that they are not able to give their own views, therefore having clear lines of communication through a process of engagement with parents, carers, staff and any future provider is essential
- Some parents and carers work during the day and may not be able to attend any engagement events that are scheduled in normal office hours and this should be given due consideration in any programme of engagement

Interim model from 1 June 2019 to present (see Appendix 1).

The priority 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, such as starting to upskill social care staff in delivering some health interventions with training, competency testing and governance development
- fully recruit social care staff in line with the revised structure
- ensure the new social care infrastructure and governance was robust
- continue to listen and learn from parents, carers and staff about what works well and what needs to change to maintain statutory responsibilities.

Procurement of a provider for the interim model:

The CCG and Derby City Council hosted an engagement event with prospective service providers. Parents were invited to put themselves forward to represent other parents and carers at the event.

The provider engagement event was held on the 10 January 2019 and was attended by a range of providers including local NHS organisations, voluntary and community sector and the commercial health sector. A parent of a service user from the Light House was present and contributed the discussions.

The purpose of the engagement event was to help commissioners shape both the long term model for the service and the provision to continue to deliver the service in the short term. The CCG and City Council shared with providers the:

- details of the service;
- range of needs of the children and young people that use the service;

- challenges of the service;
- initial feedback we'd received through engaging with parents and carers

The engagement event and subsequent direct approaches to potential local NHS providers was initially unsuccessful until the specialist healthcare provider Nurture Care were identified as the only provider with the skills, expertise and capacity to meet the requirements and timescale specified. Nurture Care was appointed to provide direct nursing care, training for Derby City Council care staff to deliver some of the roles (health care tasks) previously delivered by healthcare staff and support with new governance arrangements. Nurture Care have an CQC overall rating of 'Good' and 'Outstanding' for Caring. Both Sun and Star units are presently run by a combination of nurses (supplied by Nurture Care) and residential care workers (Derby City Council staff).

A significant benefit of this approach is that it has enabled service users, their parents and families and staff to experience a potential long term model on a short term basis, albeit on a reduced service, whilst capacity continued to be built. It has also offered commissioners and the wider system an opportunity to evaluate a potential future model of delivery. Critical factors such as quality, sustainability, performance within the budget envelope and other indicators can be tested and shared as part of the process.

It is important to note that a spot check inspection by OFSTED in July 2019 under interim arrangements awarded the Light House residential short breaks service a 'Good' rating.

For safety and staffing reasons, the interim service has operated at reduced capacity - 3 nights per week. For fairness, the decision was made to proportionally reduce respite allocations for all families. This added pressures for families, particularly in holiday time and has been and continues to be closely monitored by social care.

Moving from the interim model to a long term solution

The Light House routinely has places for around 60 children to receive short breaks. There is a waiting list of children who have not yet been able to access the service. In order for the Light House to become an efficient and sustainable service to meet the existing and growing future demand the model needs to change. The aim in the long term is to build a home from home short breaks service that meets the needs of all children and is reliable and safe by having a regular team of staff that know the children well and understand their individual needs.

The new service needs to offer:

- Better continuity of care for all children
- Consistency of service provision with appropriate levels of staffing.
- A sustainable model which 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 where they can be reassured that care is safe.

The potential longer term changes to the Light House model fall within Section 14Z2 of the Health and Social Care Act 2012 and NHS Act 2006 requirement to engage and consult with parents and carers, staff, key stakeholders including local authorities, the wider public and anyone who has an interest in this service.

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 (see engagement and consultation section below).

Engagement and consultation

The project group formed from both commissioning organisations (Derby City Council and NHS Derby and Derbyshire CCG) were determined that parents and carers in particular should be involved in a co-design role from the beginning and that has formed the core of the pre-engagement and consultation phases.

Pre – consultation engagement phase – November 2018 to July 2019

Further to the announcement in November 2018 of the incumbent health care provider's intention to give notice, the priority of the CCG and Derby City Council was to provide robust assurance that the Light House as a statutory service would remain open during the procurement of a new provider and subsequent transition phase. As it became clear that finding an alternative provider to deliver the same model was not possible.. The key channels to support the pre-consultation engagement phase are described below:

Website

Throughout the engagement phase there was a dedicated page on the CCG website which listed the background information, a link to a survey and constantly updated frequently asked questions to support responses to the survey.

Engagement events

Recognising this was a difficult and uncertain time for parents and carers, the approach to pre-engagement was primarily based upon providing regular face to

face updates and question and answer sessions for parents and carers. These were jointly led by a small team of senior officers in the City Council and CCG to ensure consistency and to reassure parents and carers that partners were working closely together. The sessions were offered on a group and one to one basis throughout and included opportunities for informal discussion through visits to the centre, coffee mornings and other routes.

Date	Activity	Comment
19.11.18	Parents/carers engagement session	Morning
21.11.18	Parents/carers engagement session	Evening
25.1.19	Parents/carers engagement session	Morning
26.1.19	Parents/carers engagement session	Evening
25.4.19	Parents/carers engagement session	Morning
29.4.19	Parents/carers engagement session	Evening
30.4.19	Parents/carers engagement session	Morning
20.5.19	Parents/carers engagement session	Evening
21.5.19	Parents/carers engagement session	Morning
8.7.19	Parents/carers engagement session	Morning
9.7.10	Parents/carers engagement session	Evening

Survey for parents unable to attend engagement events

For those parent and carers that were unable to attend any of the engagement events, a survey was created to ensure that all parent, carers, healthcare professionals had the opportunity to have their say and be part of the engagement process. Parent and carers were also able to leave any relevant questions with the Light House manager. Paper copies of the survey were encouraged to be completed and sent back to the CCG using a freepost address.

There were three key questions which required feedback (see questions below). Demographic information was also asked in the survey but due to the short number of responses this will not be included as it may result in the identification of individuals.

The CCG and City Council were keen to understand views in three areas:

1. What do you think about the Light House and the way it works now?
2. Is there anything that you think should be changed?
3. Do you have any ideas for the future?

Headline themes from the survey responses to each key area are:

Question 1:

- The Light House works well for families and is excellent
- Staff know our children well and are dedicated and they do a fantastic job for us and our child
- The Light House provides essential respite
- The Light House is a lifeline for parents and carers
- Children who visit have complex needs and the service caters for these
- We feel very frightened that you might be taking away a service.

Question 2:

- The service is operating well
- The service works well for us, so don't change it
- It's a fantastic service so why do you want to change it?

Question 3:

- Keep nurses who are suitably trained to run the service
- A better link between the Light House and the adult services
- Ensure that health and social care are working together on this service
- Has to meet the needs of the child
- Would rather not have agency staff as they don't know our child.
- We need regular updates on the procurement

Pre engagement programme summary:

The pre-engagement phase generated invaluable insight through robust and informative discussion opportunities around what matters most to service users, parents, carers, staff, providers (and potential providers) and others with an interest in the service.

It also presented an opportunity to discuss service models that are operating elsewhere and how those could potentially be modified to respond to the higher levels of dependency and physical healthcare needs of some of the young people using the service at The Light House.

There was a broad consensus of opinion amongst all who attended that any future model would more than likely need to incorporate the following:

- Some continued involvement of a health provider;
- Some continued involvement of nursing staff;
- Better integration of the staffing model and governance arrangements that would allow the development of the social care staff to take on some of the duties currently only undertaken by nurses;
- An acknowledgement that the different levels of physical healthcare need on the Sun and Star units justify having differing staffing approaches;
- An acknowledgement that staffing skill mixes should be able to be flexed from day to day to fit the needs of the group of children and young people being cared for;
- To consider if the dedicated carers some young people have as a part of their continuing healthcare package might play some role in supporting that young person during their short break.

Continuity of service delivery has been maintained during the pre-engagement phase and transition between health care providers and interim arrangements. Since April 2019 the residential service has been able to safely open 3 nights per week to ensure that the appropriate number of qualified nurses is on duty. Families would normally use this service between 2-5 nights per month per child based on assessed need.

An extension to the recruitment programme meant that families continued to be offered less than the full allocation up to the end of the consultation period. Attracting high quality staff has been challenging and the CCG, City Council and parents and carers have not been willing to compromise on the high standards of skills and experience specified and needed to deliver the quality of care desired for the potential new model.

The experience of parents and carers during the pre-engagement phase indicated that it was a challenging time for both families currently using the service and those on the waiting list (eleven families), as their needs could not be accommodated until staffing reached the appropriate level.

The impact on families has been closely monitored through social workers with advice and support offered where possible. The recruitment programme continued to the end of the pre-engagement phase and then into the consultation phase.

Feedback indicates that at the closure of the pre-engagement phase social care staff in post reported that they were finding their new and developing roles and responsibilities satisfying with the right support being offered. Supervision and feedback from trainers was positive. The development of a framework for social care staff to deliver appropriate health tasks under local authority governance was on

track. As there was a robust model in place, there was a confidence that if approved, once staff are recruited, trained and competency assessed then the number of nights offered to families would be extended and this formed an important element of the consultation phase.

Formal consultation phase

Following an evaluation of the pre-engagement programme the joint project team of Derby City Council and NHS Derby and Derbyshire CCG 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” further 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

The draft consultation document was submitted to the governance processes of both Derby City Council and the NHS Derby and Derbyshire CCG as described below, requesting permission to co-consult. The 15 questions can be seen in Appendix 2:

Date	Action	Comment
8 April 2019	DCC Improvement and Scrutiny Panel	Present update
April 2019	Update to Cabinet DC Member lead for the Children and Young People	Update on the consultation plan
1 August 2019	CCG Governing Body	Approval to consult
8 August 2019	CCG CLCC	Clinical reassurance
4 September 2019	CCG Engagement Committee	Approval to consult
21 October 2019	Paper delivered to the Children and Young Peoples Scrutiny Panel	Mid-point of the consultation process

The key dates for the consultation phase were:

Date	Action	Comment
5 September 2019	Consultation launch	See list of promotional channels below
5 September to 3 December 2019	Ongoing promotion of a range of face to face and other opportunities for parents, carers, partners and stakeholders and others to get involved and provide comments and feedback	See table below
3 December 2019	Consultation closed	Start report draft
4 December to 31 December 2019	Consultation report draft	Jointly prepared by DCC and CCG teams

8 January 2020	Engagement Committee	Consultation report and recommendation for approval
20 January 2020	Derbyshire County Council Improvement and Scrutiny Panel LA	Consultation report and recommendation for approval
23 January 2020	Clinical Lay Commissioning Committee CCG	Consultation report and recommendation for approval
6 February 2020	Paper to DDCCG Governing Body	Consultation report and recommendation for approval
24 February 2020	Derby City Council children's Overview and Scrutiny, LA	Consultation report and recommendation for approval

Direct targeting of parents and carers, partners and stakeholders, networks and others formed the core of the consultation programme and the groups in the table below were directly targeted at launch and repeated again during the consultation phase via the channels described:

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

The schedule of key dates in 2019 for face to face events is outlined below:

Date	Action	Comment
26 September	Parent and carer Forum at St James Centre – Funability	Informed parents and carers about the consultation and distributed the survey and model information
7 th November	Disability Equality Hub	Closed group for Derby City Council
11 November	Parent and Carers meeting at the Light House	5 parents attended
14 November	Parent and Carers meeting at the Light House	Cancelled due to flooding in Derby city
18 November	Parent and Carers meeting at the Light House	Cancelled – no take up from parents and carers.
19 November	Programme of follow up calls	To parents and carers unable to attend the face to face sessions
3 December	Consultation closed	Start report draft

Other promotional channels for the consultation include:

Website

The Light House consultation was listed on the CCG website www.derbyandderbyshireccg.nhs.uk –. The survey link, along with the relevant information, was included. Derby City Council - www.derby.gov.uk/ also had a page on their main website where the survey link was listed.

For the duration of the consultation a total of 816 people visited the pages.

Facebook:

- 5th November - 199 people reached and 1 person clicked on the survey link.
- 15 September - 144 people reached, 4 likes, 3 shares of the post, 2 clicks on the post
- 12 September - 120 people reached, 1 comment, 1 share of post 6 people clicked on the link

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)

Twitter:

Regular tweets were issued via the CCG and DCC Twitter accounts and re-tweeted by others based upon the example below:

 NHS Derby and Derbyshire CCG @NHSDDCCG · Nov 5 The Light House is jointly commissioned by CCG and Derby City Council. A formal consultation has begun and you can have your say: buff.ly/2ZQ4LTO View Tweet activity	542	6	1.1%
 NHS Derby and Derbyshire CCG @NHSDDCCG · Oct 31 A formal consultation has been launched about The Light House in Derby city centre. Have your say by completing the survey: buff.ly/2ZQ4LTO View Tweet activity	549	3	0.5%

CCG Intranet:

The survey and consultation link was also listed on the website for CCG staff and GPs.

Frequently asked questions:

Questions emerged throughout the engagement and consultation phases and these were logged and also published with responses on websites where the questions were repeated. They can be seen in Appendix 3.

Analysing the consultation feedback and results

The following key points help to set the context for the analysis:

1. There are 48 service users, families and carers accessing the service plus a waiting list averaging 17 during the consultation phase. Whilst there are other interest groups such as social workers, partner organisations, these are a small cohort and the service is not generally of interest to the wider public
2. The pre-consultation engagement programme phase was extended to ensure that there was a full understanding of the impact of the interim service. The intensive activity which took place during that time and the feedback of those with the greatest interest meant that they had provided detailed feedback as part of that process and had little or nothing to add through the consultation programme. Attendance at the face to face events was low when compared to the pre-consultation engagement phase and despite follow up contacts via letter, email and telephone there was a low response in overall terms with parents and carers citing “engagement fatigue” and “nothing new to add” as the main reasons.

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
<p>Families who have a child at the Light House</p>	
<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>
<p>Q3 Are there any parts of the Light House 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 	<p>The service has a defined budget envelope and 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</p>

<ul style="list-style-type: none"> • 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>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 ie 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 eg 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 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 would have liked a return to more nights. The concerns when expressed were around clinical assurance as is Q6 below.</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 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

	<ul style="list-style-type: none"> • Enteral feeding (via gastrostomy) tubes • Medication administration eg 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 important • 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 	<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>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</p>

<p>supervision and training in place for staff</p>	<p>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 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 	<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 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</p>

<p>Rainbows Hospice where there is a clear 'crisis' criteria</p>	<p>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 (ie 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 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,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>

Recommendations

NHS Derby and Derbyshire CCG and Derby City Council recommend that the proposed model of delivery for the Light House is approved and implemented. This is further to the delivery of intensive programmes of engagement and consultation co-designed and produced with parents and carers, partners and stakeholders.

The table below summarises the old and proposed model and potential benefits of 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 care staff trained in child specific interventions trained and supervised by nurses- 44 children	Bespoke packages of care for children with most complex needs 4 children	Better continuity of carer Better quality of social experience Improved flexibility and increased availability of service

The new service would mean:

- Better continuity of care – for the majority of children and young people 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 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 – appropriate levels of staffing 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.

Respondents have told us that it is really important that whoever is providing care for a child should know them well regardless of the level of need with a robust care plan being in place. This means knowing what's normal for that individual child and being able to recognise when a child is becoming unwell. Sometimes these signs are subtle and are only recognised by someone that is working with the child on a regular basis.

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:

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

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

- Known carers/continuity of care/r will provide the most 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

The potential developments under consideration¹ for children where the most complex needs are present are:

1. Nurses on site when a child with the most complex needs is resident.
2. Care following the child - extend existing continuing care packages so that known carers look after the child during their stay at the Light House.

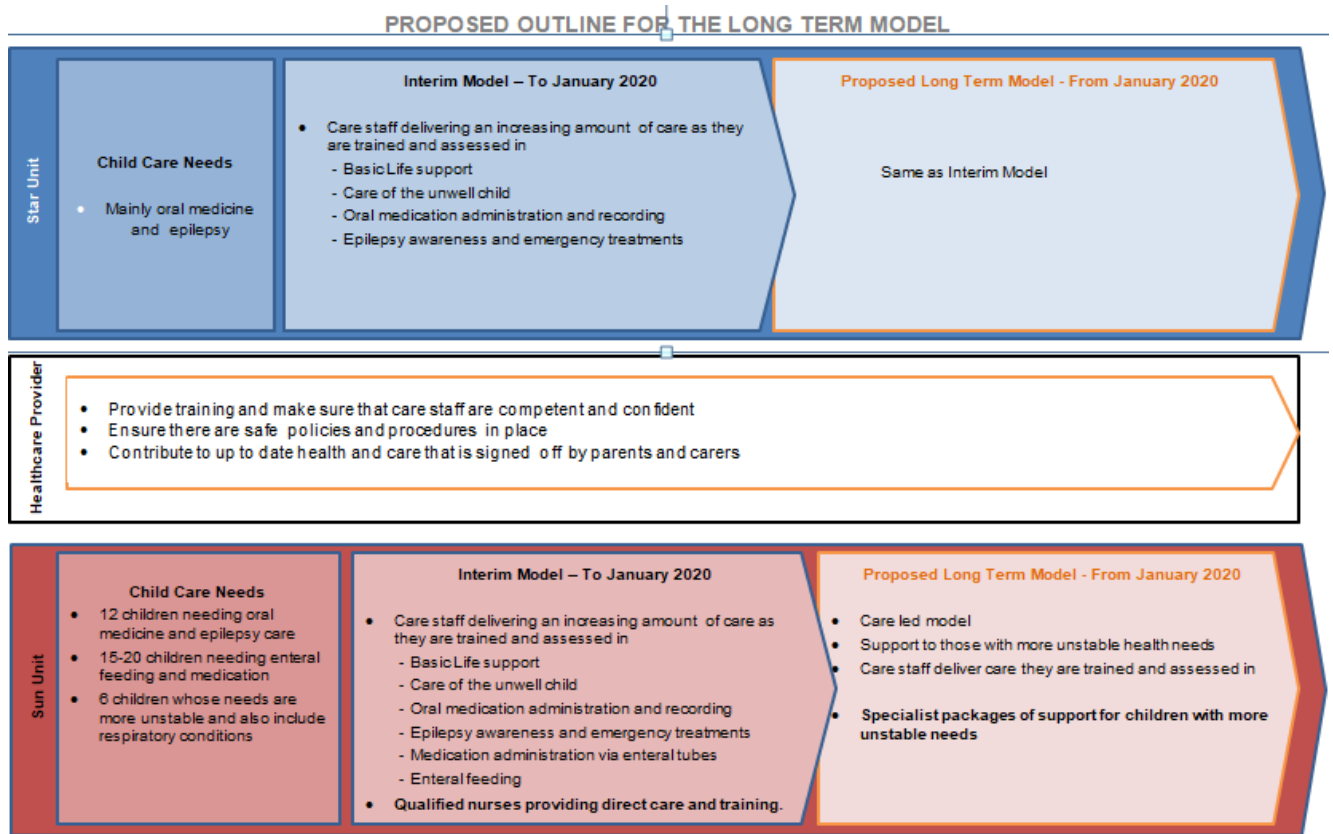
Next Steps

If approved the new model would start the implementation process immediately as part of a detailed implementation plan. The intention would be to have the full model embedded by April 2020.

¹ 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 to ensure that care is safe.

Appendices

Appendix 1 - diagram illustrating the potential long term model



Appendix 2 - 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 3 - frequently asked questions displayed on websites

When will the LH open more than 3 nights?

At the moment we are working really hard to increase the amount of nights that we are able to offer. As you might be aware, we are working to recruit high quality staff and ensure they are given adequate training to be able to work and care for children who use the Light House. Derby City Council is developing strict guidelines and putting policies in place for staff to be able to deliver key health needs such as enteral feeds. Once these have been approved by Derby City Council and the CCG, staff will then be able to provide this level of care.

Will nursing nights continue after Christmas?

We are working closely with NurtureCare regarding the options and the staffing rota for the New Year. Our priority is to maintain the service after Christmas

Are there any other alternative respite options after Christmas to use in Derby and Derbyshire?

There are other places that provide social care led services for example The Getaway in Ilkeston who accept children with the same types of needs at the Light House apart from those with the most complex physical care health needs.

Why are not parents involved in the recruitment process at The light House?

The City Council have been following approved HR processes for the recruitment. The interview panel consists of key members of Light House staff along with a parent/carer. If you have additional questions please contact Sam Watts – Manager, The Light House.

What's the care planning process, how's in being done, how are health professional involved eg KITE, OT, physio?

All parents and carers have a detailed care plan for each child that uses the Light House. The care plan includes all the relevant information for that child which staff at the Light House need in order to give that child the best care. For example; personal information about the child's day, what type of care they need, what to do in a crisis, These are approved and signed off by each parent/carer and staff at the Light House.

What can parents and carers do in a crisis?

Parents and carers must follow their detailed care plan, This will include details of what to do in a crisis. There has been no change to this. The only changes will be if health professionals known to the child make any recommended changes. Any general concerns about care should be directed to Sam Watts the Light House Manager. Any specific queries about health care at the Light House should be to Zoe Walters lead nurse from Nurture care

Is the recruitment complete for staff at Light House?

Derby City Council staff have been working really hard to ensure they get the right staff working at The Light House. They are leading on the recruitment are gradually recruiting staff new staff. It's important we get the right people, we need high quality and can't compromise on speed. We want to do it once and do it well. We are aware it is taking longer than expected. There are will be another round of interviews in early November. Once staff have been appointed they then need training which can take between 6 weeks to 3 months depending on their skills and where they have worked before.

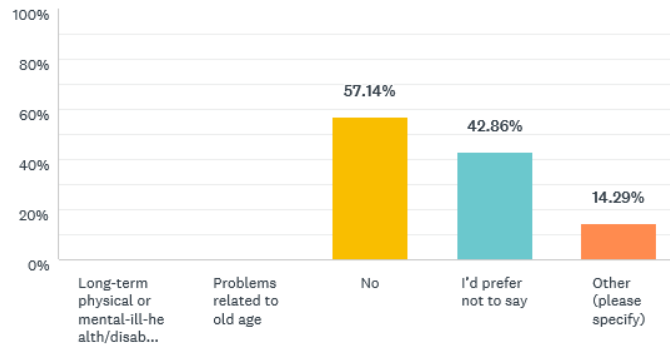
How is the staff training going?

Derby City Council staff are working really hard alongside NurtureCare to train staff to a very high standard ensuring that no child is at risk and therefore cannot compromise each step of this long process.

Appendix 4 - survey respondent background information

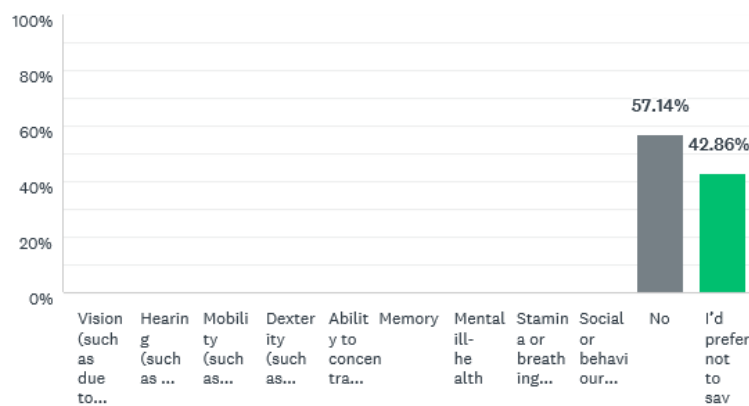
In addition to your child (who accesses the Light House) do you look after, or give any help or support to family members, friends, neighbours or others?

Answered: 7 Skipped: 2



Are your day-to-day activities limited because of a health condition or illness which has lasted, or is expected to last, at least 12 months? Please select all that apply.

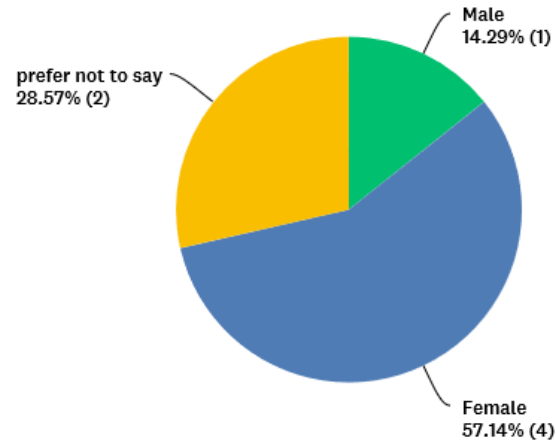
Answered: 7 Skipped: 2



Appendix 5 - Equalities Data

What is your Gender?

Answered: 7 Skipped: 2



Please choose one option that best describes your Ethnic Group or Background?

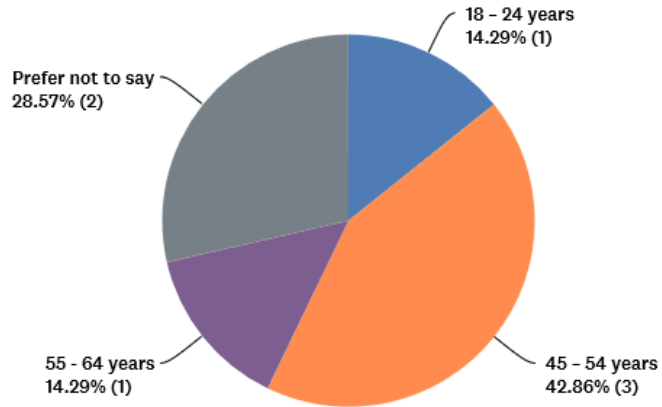
Answered: 7 Skipped: 2



- White - English/Welsh/Scottish/Northern Irish/British
- White - Gypsy or Irish Traveller
- Mixed/multiple ethnic groups - White and Black Caribbean
- Mixed/multiple ethnic groups - White and Black African
- Mixed/multiple ethnic groups - White and Asian
- Mixed/multiple ethnic groups - Other
- Asian/Asian British - Pakistani
- Asian/Asian British - Chinese
- Black / Black British - African
- Black / Black British - Other
- Any other ethnic group, please describe:
- White - Irish
- White - Other
- Asian/Asian British - Indian
- Asian/Asian British - Bangladeshi
- Asian/Asian British - Other
- Black / Black British - Caribbean
- I'd prefer not to say

What is your age group? (optional)

Answered: 7 Skipped: 2



Please choose one option that best describes your relationship status:

Answered: 7 Skipped: 2

