Foreword from the Director of Children’s Services

Within the Northern Trust area we know that 98% of children with disabilities live at home, supported by their families. We know that respite arrangements are very important and are valued by parents and children. We have been consulting on why we believe we need to modernise our respite provision and consolidate our residential based resources on two sites, Whitehaven and Rainbow Lodge, to ensure safe effective residential care whilst we progress our plans to increase our range of respite services.

We met with parents of the children who use Cherry Lodge and listened to the views expressed. The parents told us how much they and their children value the respite they receive. We know that there will always be a need for some residential respite services but parents and carers must be involved as we plan for the future. We have also formally consulted on our proposals for twelve weeks.

This report describes the consultation process and gives a summary of the feedback we received.

I want to thank everyone who gave us feedback during this consultation. I would particularly like to thank the parents and carers for taking the time to meet with us.

Marie Roulston

Director Children’s Services
Background

We believe that children and their families would benefit from a wider range of more flexible respite services, which would enable greater choice and fairer access, while still maintaining the option of overnight residential care. We also need to develop respite services for children with complex physical health care needs.

We have recently experienced difficulties in retaining consistent levels of suitably qualified staff to ensure that essential standards of care and safety can be maintained consistently in our children’s residential homes for respite. These safety concerns led to the temporary closure of Cherry Lodge in May 2013 with respite being offered from within Whitehaven, through Direct Payments, from the Sharing the Care Short Break Service, through day care and domiciliary support or a mix of a number of these alternatives.

Over the last months there have been individual meetings with parents and carers of children who have used Cherry Lodge to find out how they feel about the alternative respite arrangements they have received since the home was temporarily closed. On the basis of what we have heard from the parents and carers, and because of the likelihood that we could not guarantee consistent levels of respite in future, the Trust has been considering the long term future of the home.

We would like to be in a position to offer more flexible respite options to suit the changing needs of individual children and families. One way of doing this would be to combine our resources to continue to provide residential based respite from within Whitehaven and Rainbow Lodge. We will continue to provide respite through our Sharing the Care Short Break Service and progress our plans for increasing our range of respite services. Arrangements for those families who are supported within their own homes would not change.

Our future plan is to have a purpose built respite home in a central location in the Trust. We would envisage a purpose built home that would be a resource centre for children and families throughout the Trust area that could accommodate all children with disabilities who need respite care. We have listed this development as our priority for capital investment with the Department of Health, Social Services and Public Safety. In April 2014, we will begin to develop an outline business case for this and we would welcome participation from parents, carers and others in this project.
The consultation process

Before formally beginning the consultation, extensive work was done to ensure the families that receive respite from Cherry Lodge were fully informed of and consulted on our plans. Individual meetings were offered to families and carers directly affected to gather their views on respite services for children with a disability.

On 3 March 2014 we commenced a public consultation on our proposal for ‘Future of Respite (Short Breaks) Services for Children with Disabilities’. The consultation closed on 26 May 2014. This report should be read in conjunction with the consultation document which can be found on our website.

Consultation documents were made available on the Trusts’ website (i.e. available to the public) and intranet (i.e. available to Trust staff). Documents were also available in hard copy or in different formats on request. In addition, meetings were set up with carers to discuss our proposals and to establish if there were particular concerns at any stage of the process. These face-to-face meetings proved fruitful and informative for those developing the proposals.

A consultation letter was sent to consultees on the Trust’s consultation database and to the families and carers affected by the proposal. All consultation materials were placed on the Trust’s website and Staffnet.

All those listed in the HSC Trusts’ Section 75 Consultation Database (777 groups and individuals) received a letter informing them of the Trusts’ consultation arrangements. A letter was also sent to consultees reminding them that the closing day for consultation was 10 May 2013.

A total of 12 written responses were received during the formal 12 week consultation. It is important to recognise that many of these responses were very detailed and informative and the face to face meetings with the families and carers provided an opportunity for direct engagement with those affected by the proposal before the public consultation process.

Equality Impact Assessment

All public bodies have a duty to examine the equality aspects of their decisions and the Trust’s Equality Impact Assessment (EQIA) was carried out to identify the impact of the proposal and how it should be addressed. The EQIA was consulted on at the same time as the consultation document. A copy of the EQIA can also be found on the Trust’s website.
Meetings with staff

We recognise that the key to success in major transformation is the involvement of staff. We have met with staff over the last months and have established processes to make sure that staff can raise issues and are involved in the on-going implementation of the proposals.

Staff in Cherry Lodge, as well as Trade Unions, were engaged throughout the development of our proposals and during the 12 week formal consultation they were made aware of the availability of the consultation documents via internal staff engagement processes.

Consultation feedback

Feedback from meetings with parents and carers

The key themes that emerged from meeting with parents and carers were as follows.

- Despite some parents’ initial hesitancy in moving their child’s respite service to Whitehaven, the experience has been very positive, with some parents stating a preference for their child to remain there even if Cherry Lodge was to re-open.
- Children appeared to settle well within their new respite environment and found Whitehaven stimulating with a wider range of activity choices
- Assistance with transport to respite is valued which along with consecutive nights of respite makes the break for carers more meaningful
- A homely environment is essential should the Trust be successful in its plans to progress with a purpose built residential respite home
- Alternatives to residential respite have been successfully established and continue to be developed
- Establishing positive working relationships between parents and the residential home is important in providing reassurance to parents
- Ongoing communication with social workers and other key professionals involved in the child’s care plan is essential
- Transition from children’s services to adult services is a concerning time for parents and carers and this needs to be carefully planned well in advance by all professionals and the child and parents fully involved in the transition process.

In conclusion, parents and carers told us that they recognise that it is not always possible to provide respite care in the same way for all families due to the geography of the Trust. Respite is most beneficial when it happens in consecutive days/ nights.
Written feedback

This section of the report summarises the written responses we received. The responses have been categorised into emerging themes.

Trust’s overall proposal

• Support the proposals to review short break services to ensure that they are equitable, safe, and sustainable and offer value for money.

• This is an important and crucial development which needs to be accessed by all children and families based on their needs.

• For parents and families of children and young people with a learning disability, autistic spectrum condition and acquired brain injury, short breaks are an essential service

• Agree that it is important to review services to ensure that they meet and can respond effectively to the increasing needs of children with disability, including children and young people with a learning disability, and their families.

• Across Northern Ireland, short break services could be improved with greater availability and more options available in local areas.

• Concerned at lack of information in the consultation documents with regard to the current operation of respite services, the numbers of children with disabilities and the types of disabilities and the importance of carer assessments.

• Concerned there is little reference to addressing unmet need, gaps in service provision or to ensuring an increase in the provision of short break services or greater promotion of direct payments or self-directed support.

• Trust should provide more detail on how its review of services will result in more and better provision of short breaks and meet the growing demand and need for short break options, the impact on children and young people.

• The proposals should take account of how short break services are managed and accessed where there is more than one family member with a learning disability or disability.

• To ensure safe placement of children with complex medical and/or physical needs, a paediatric Occupational Therapist needs to be consulted to ensure that the child is managed safely in activities of daily living i.e. consideration is given to child’s position for feeding, play and personal hygiene.

• It would be inappropriate for children and their families who are used to receiving residential respite to have it taken away
• No information about the number of placements that will be permanently lost as a result of this proposed closure of Cherry Lodge or about the impact that this will have on children with disabilities and their families within the Trust area. In addition, no information has been provided about how the Trust aims to address the deficit of placements as a result of the proposed closure of this facility or to staff the proposed new facility.

• In the absence of data in the consultation document on the numbers of children in the NHSCT with disabilities we can assume that, based on the Northern Ireland average, which is 6% of children have a disability, the NHSCT has responsibility for service provision for approximately 6,558 disabled children and young people - it is therefore surprising that currently 125 families receive respite services through the Sharing the Care Short Break Service, which we understand to be a voluntary scheme, for day and overnight care, with 55 families receiving respite through Whitehaven and 22 from Rainbow Lodge. From a cursory analysis of these figures it would appear to suggest a deficit in service provision for respite services given the large number of children with disabilities in the NHSCT.
Trust Response

The focus of the consultation document was to outline the challenges faced with current residential respite provision and a way forward rather than on the current operation of respite services. The business case that the Trust will develop for the purpose built unit however will include a strategic context with detailed data and analysis of the numbers and needs of children with a disability across the Trust area, along with current types of respite provision that will highlight deficits in service provision and assess options for future services. This process will also map the current access arrangements and how our current developments within short break services have progressed. The Trust will ensure that the Occupational Therapy Service is involved in the safe management of children with complex medical and or physical needs.

The Trust will welcome input to the development of robust data by representative organisations and individuals. It was not appropriate to include detailed information in the consultation document relating to those directly affected because of small numbers involved.

Children in receipt of residential respite will continue to receive this service if they are assessed as requiring it. No residential respite placements will be lost as a result of Cherry Lodge permanently closing. Residential respite provision has been and will continue to be offered from Whitehaven.

The Trust has specific dedicated services for children with disabilities with four social work fieldwork teams and one Sharing the Care Team Trust wide. In addition there are currently two residential respite homes. Prior to accessing respite services a UNOCINI assessment is completed in respect of the child and their family. This incorporates an assessment of the carer circumstances and needs. The assessment tool (UNOCINI) used for all children with disabilities and their families advises parents of all available services including direct payments. The Trust actively promotes choice and options in relation to respite service including direct payments.

Unmet need is recognised by the Trust’s Children Disability Resource Panel where the majority of provision of services for children with disabilities are approved and progressed.
All assessments undertaken in relation to children with disabilities is multi-disciplinary and all needs including medical, occupational therapy and speech and language are considered and addressed within the child’s specific Care Plan. Advice and training from a range of professionals is provided on a child specific basis prior to any respite arrangement being commenced. Key professionals are invited to formal reviews in respect of the child’s care package and changing needs. Collaborative working is considered best practice and actively promoted and practiced within the Trust.

Children’s respite arrangements are reviewed on a regular basis and their parents fully involved in the process. Any changes in respite arrangements are only recommended and implemented if deemed in the child's best interest.

Cherry Lodge was providing a respite service for 18 children prior to its temporary closure in May 2013. All these children were provided with alternative respite arrangements that reflected their current level of respite and in some instances increased and or improved their provision. The staffing levels were immediately increased within Whitehaven respite home to absorb the shortfall in 3 beds at Cherry Lodge and this arrangement will continue.

The Trust recognises the need to review and develop its respite services for children with disabilities on an ongoing basis and acknowledges the demand and pressures on available resources. All care packages of services including respite are formally reviewed on at least 6 monthly basis under formal policies and procedures. Client user and carer feedback is sought regularly both on a formal and informal basis. The need for more specialised family based respite for children with complex needs is being developed.

There are a number of families known to the Trust where there is more than one child within the same family with a disability. Professionals are mindful that if different respite services are in place in respect of each child that these are co-ordinated for the best management and benefit to the family.
Development of a wider range of age appropriate day support and respite/short breaks

- Choices from a wider range of alternatives are important to meet the varying needs of children / young people and their families.

- Choice and variety of options and alternatives for short breaks are important - short breaks mean different things to different people so there is a need to be flexible to meet the needs of everyone.

- The needs and circumstances of disabled children are extremely varied and this must be reflected in the types and extent of respite services available.

- Welcome a move to provide a wider diversity of options for children and their families including day support, community activity and residential care.

- Fairer access should not mean that fewer families receive residential respite

- Families continue to stress the inadequacy of short break provision for the duration they need a break, when they need it or in a way that is directed by them.

- Welcome the commitment to work in partnership with parents, children and young people, organisations in developing a range of short break options.

- For parents and family members, short breaks are a break for the child / young person and a chance for them to spend time outside their normal living space; a chance to socialise with others and experience new things within a secure environment; and also preparation for an independent future.

- Important that short breaks are flexible in terms of booking, confirmation and emergencies.

- Important to ensure regular breaks and availability of longer periods of short breaks.

- Short breaks help families and children to build resilience, develop peer support networks, provide opportunities to share concerns and identify needs and avail of further support.

- Children and young people need to be involved in decision-making about their day time activities and short breaks.

- Historically the Mid Ulster area has been neglected in terms of residential services for children with disabilities and it is vital that there is a major hub of resources within easy access.
• An excellent plan but one which will need to be backed up by fast and effective action - the current level of services is not meeting the needs of children and their carers in the Mid Ulster area.

• There is limited information available about the planned provision, including the profile of services, location, links with education, leisure opportunities, eligibility and access criteria, as well as transition arrangements between and within provision and into adult short break services.

• Better information required on the availability of respite services and information about how to access the services.

• The development of Sharing the Care Short Break Service does not have an opportunity for open procurement/ tendering process to allow for other service developments to be considered - Trust should look beyond their service provision and allow competitive tendering for additional short break service development in the area.

**Trust Response**

The Trust is committed to providing a range of respite/short break services to meet the diverse needs of children and their families and to ensuring respite/short break services are accessible to all children and families in the Trust area. Children and families who are assessed as requiring residential respite will continue to receive it.

The Trust recognises the importance of short breaks for families and is committed to working with children, young people and their families to ensure they receive respite that meets their assessed needs and to help develop a range of flexible respite services.

The development of a business case will profile all services across the Trust’s geographical area as part of the process of identifying gaps and options for future services.

Respite services are accessed through the Children's Disability Team and options available for individual families are discussed with them during the assessment process.

The Trust is committed to ensuring that information is available to the public about the services it provides and would welcome specific input to ensure its website is up to date and relevant.

The future development and planned expansion of short break services may in future provide opportunity for partnership working with voluntary and other community organisations. This would be subject to appropriate procurement processes.
Development of replacement purpose built respite unit

- A central location may not be equal to all as there may be a greater need in certain areas more than others.

- A single short break building in a central location will present significant challenges to many families in terms of accessibility - research indicates preference for locally accessible short break services.

- Consideration must also be given to enabling children / young people to access their usual activities while at this short breaks building. For some, remaining in routine is important, and for others, new and different things would be beneficial - this is very much an individual decision that the child / young person and their family must be involved in making.

- Support the Trust’s proposal to develop alternatives to buildings based respite, however, the proposal regarding building based respite will mean this service is less accessible.

- The current Residential Respite Units are geographically too far from many of the children and families in the Cookstown district - transport costs to and from the existing Units are huge and it is exhausting for children and parents who have to make the journeys.

- Not an attractive option for families to leave their child at a Unit far away from their family and far from their school and local community.

- Concerned that the Trust propose to build a replacement respite unit in a central location as they already have 2 residential units available.

- The care provided in Whitehaven is safe and effective and provides a vital service for parents and families of children with disabilities - without this overnight respite care many families would be unable to cope with their child.

- Residential overnight stays are expensive in comparison to home based and community based support – concerned that the building of another residential unit will not offer value for money and is in contrast to the vision of Transforming your Care- delivering care in local community, reduction in institutional care and the personalisation agenda.

- Welcome the proposal to develop purpose built respite provision that is fully accessible but more detailed information required on the proposed short break provision including the number of places, the number and ages of children and young people who will access the service; the numbers of families supported; its location; eligibility criteria and access arrangements; as well as the impact on children and families who access current residential provision.

- Suggest that, due to the large geographical area served by the Northern Trust area, it may be preferable to establish 3 or 4 smaller residential facilities,
serving smaller geographical locations and more likely to be closer to a child or young person’s own home and community.

- More information is required on the alternatives available for families who live furthest away from the planned provision.

- There is a lack of information on how to access assessments for services or a Carers Assessment and how decisions are then made about their respite based on those assessments.

- Require information on timescales for the development of a purpose built respite unit in a central location, the likelihood of getting funding for the development and the sustainability of the unit with regard to running and staffing costs.

- Occupational Therapists input vital in the planning of this respite unit, to facilitate children with many complex needs.

**Trust Response**

Our future plan is to have a purpose built respite unit in a location that is accessible for all children in the Trust area. We would envisage a purpose built unit that would be a resource centre for children and families throughout the Trust area that could accommodate all children with disabilities who need respite care. The location of the purpose built respite unit will be determined by a full business case and option appraisal and the Trust will be establishing a working group to develop this and will welcomes involvement of parents, carers and representative organisations on the working group. The future location of available residential respite units will be considered during the development of the business case which will include input from the Trust Occupational Therapy Service.

The Trust’s priority is to provide equitable, safe and sustainable residential respite services and it is important to note that this is more difficult to ensure in smaller respite units.

All families who undergo the assessment process are provided with information on the options available and the decision making process is also explained.

The Trust’s submission to the DHSSPSNI for a purpose built facility for residential respite has been positively received however at this point no definitive timescales can be confirmed. Sustainability of the unit with regard to running and staffing costs will be determined through the development of the business case.
Transport

- The issue of transport to and from respite is frequently raised with us, especially by families who reside in rural locations who would prefer respite services to be available in their own locality.

- Not appropriate for a child to travel in a bus for longer than 30 minutes so may need a number of locations. Also during holiday time the parents have to transport their child and this may have implications for families unable to do this.

- Travelling to and from short breaks can reduce the overall break for the family and young person.

**Trust Response**

The Trust endeavours to provide support with transport as identified through the assessment process and has put in place a number of arrangements to mitigate the impact of travelling long distances.
Monitoring the provision of short breaks

- The outcomes of short break provision must mutually benefit the parents and children and outcomes must be measured in this way rather than purely quantitative data of hours and sessions.

- We would welcome, too, information on Trust plans to monitor access and benefit by children and young people of different ages of the different choices and options available.

**Trust Response**

The Trust is committed to continually monitoring its services through the care planning process which involves children in the receipt of respite and their parents and carers.
Engagement with parents/carers, children and young people

- More information is required about the experiences and views of children and young people and families who previously accessed Cherry Lodge, those who currently access the options available and those who may have accessed the provision if it had continued to be available.

- The consultation document states that NHSCT staff have met with parents and carers of children who have used Cherry Lodge to find out how they feel about the alternative respite arrangements they have received since the Unit was temporarily closed yet no information from these meeting and discussions has been provided in the consultation document preventing respondents to the consultation from having access to these very important views.

- Welcome more details on the Trust’s plans to involve young people in decision about their life, to consult them directly about their preferred support options and to enhance the provision of information, advice and advocacy to ensure that their views and the views of their families are heard.

Trust Response

Information on the views of parents and carers who used Cherry Lodge is provided on page 5.

The Trust current seeks feedback from parents, carers, children and young people as part of the care planning process and will be focusing on how best to involve our users so that we get their direct views as part of our formal project planning process.
Other comments – suggestions

- Need for robust consideration of the learning, development and support needs of staff who will be delivering care within the proposed range of settings - any changes to service delivery should include staff development.

- Some young people access respite through Direct Payments and concerns have been raised regarding the level of direct payments allocated, the difficulties in recruiting suitable direct payment workers and implications for becoming an employer.

- Families are uncertain about how to challenge decisions about their assessed need. The Trust’s internal complaints mechanism is the main method of challenge available for the carer which is a lengthy process and ineffective as families often require decisions to be made about the respite in a timely manner.

Trust Response

The Trust is committed to ensuring staff are trained and have continual professional development to ensure the delivery of safe services.

Prior to accessing respite services a UNOCINI assessment is completed in respect of the child and their family. This incorporates an assessment of the carer circumstances and needs. It includes an assessment of feasibility in relation to individual’s capacity to manage a Direct Payment arrangement. All arrangements are subject to ongoing review. The issues raised in the consultation feedback are known to the regional forum that is currently reviewing the Direct Payments policy and procedures.

Once an assessment has been completed the decision on allocation of services is made by the Trust’s Children’s Disability Panel. If a parent or carer is unhappy about this decision they can contact their social worker or the team leader for clarification or further discussion. If they remain unhappy with the decision, the complaints process provides the opportunity for decisions to be challenged formally.
Equality Impact Assessment

- Persons of different marital status: some young adults may be married

- Persons with/without dependents. While all the children we support are dependents, some of the young adults may live or wish to live independently or indeed may have children of their own.

- Accept that the small numbers of people involved makes it difficult to produce information but would welcome more information on extent to which the proposals will meet the needs of children who are 10 years or under, or 17+ years; children and young people with behaviours which challenge; children and young people who are waiting to be discharged from hospital; children and young people with autism, carers caring for more than one child with a disability; the growing population of families from eastern European countries and current levels of unmet need.

- Would welcome information about how issues around inequalities in access due to the large geographical reach of the Trust are going to be addressed and Trust plans to monitor equality of access and benefit from the resources available.

- The EQIA which has been carried out as part of this consultation does not properly examine the impacts the proposed permanent closure of Cherry Lodge will have on children with disabilities and their families in the NHSCT area - policy aim of providing flexible respite services that ensure the child is at the centre of service provision and families are supported in their caring role does not adequately reflect what is actually being proposed, i.e. the permanent closure of Cherry Lodge.

- The age bracket 11-16 currently stated in the consultation is not reflective of the age range of children and young people living with cancer and would limit support available to all those children and young people affected by cancer. The Cancer Fund for Children supports children and young people aged 0-24 years in line with government guidelines and best practice – NICE 2005 ‘Improving Outcomes for children and young people with cancer’
Trust Response

The Trust completed the Equality Impact Assessment of the proposal in line with the Equality Commission for Northern Ireland Section 75 guidelines. The Trust is mindful of the lack of information available for some of the equality categories and it continues to work regionally, with other health and social care organisations, to improve the availability of statistical information. The 12 week consultation on the EQIA enables consultees to identify any adverse impact in relation to the 9 equality categories and allows the Trust to make a judgement on the extent of the impact on Section 75 groups.

The Trust is committed to providing a quality residential respite service for all those in the Northern Trust assessed as requiring it. We continually work with families to ensure that their respite services are accessible and meet their needs. Our current residential respite provision is not provided in a central geographic location which is why we propose to build a purpose built residential respite unit in the Ballymena area – thus improving access to the services for all those in the Trust area.

The Trust met with families and carers who will be directly affected by the proposal to determine the potential impact. It would not be appropriate to include this information in detail as given the small numbers of individuals, the information could be identifiable could be identified.

It is important to note that the business case that the Trust will develop for the purpose built unit will be supported by a full EQIA which will be subject to public consultation.
Next steps and timeline

The Trust has considered all the feedback provided throughout the consultation process in full and a decision was made to proceed with the proposed changes.