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 the parents and the children. Respite offers parents the time and space to devote to other family members and to deal with everyday life. It also provides the opportunity for children and young people with a disability to experience new opportunities and make new friends.

This consultation document sets out why we believe we need to modernise our respite provision. We hope through the proposed changes to be able to offer better, more flexible and tailored care. We need to be able to offer a range of respite services to children and families. We are proposing to consolidate our 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 believe that children and families would benefit from a wider range of services.

We look forward to the period of consultation to give us an opportunity to listen to views and to develop services taking account of these views.

Marie Roulston

Director Children’s Services
About the Trust

The Northern Health and Social Care Trust became operational on 1 April 2007. The Trust covers ten local council areas and provides services for a population of approximately 460,000, including approximately 109,363 children aged 0-17 years.

The Trust provides a range of health and social care services for children with disabilities, some are provided within health and social care facilities, and some within children’s own homes.

Our mission statement

“To provide for all, the quality of service we expect for our families and ourselves.”

Background

What are short breaks (respite)?

The Department of Health, Social Services and Public Safety describe a short break or respite service as “any service which allows a disabled child to have enjoyable planned experiences away from his/her primary carers and gives carers a break from their caring responsibilities”.

Respite services provide opportunities for disabled children and young people to spend time away from their primary carers. They allow parents and carers the time to spend with their other children or to deal with everyday life. The children and young people may need extra care and support at home. There are several ways that carers can get a break, either through families or friends, or voluntary organisations that offer a few hours of support each week. Services provided by the Trust can include day, evening, overnight and weekend activities and can take place in the child’s family home, the home of an approved carer or in a residential or community unit.

Why we need to change the way we currently provide respite services?

Respite services are of immense value to children and their families but we know that families will have different preferences as to the type of service that is most helpful for them.

There is an increasing demand for respite services and the needs of children and families has changed, so the way in which we provide our services needs to be reformed so that the assessed needs of children and their families can be met in a fair and consistent way.

We have carried out an initial scoping exercise of how we currently provide respite services and we know that current services do not match the changing needs of
children and families. We know that many families who receive direct payments for social services are moving away from using traditional overnight care.

It is important to recognise that this proposal is driven by a need to make sure that we provide services that are equal for everyone that are safe, sustainable and are value for money.

Transforming Your Care, A Review of Health and Social Care in Northern Ireland, concluded that there is a need for change in the way services are delivered to manage increasing demand, deliver high quality, evidence based services that provide child centred care. One of the key proposals outlined in the document is further development of a more diverse range of age-appropriate day support and respite and short-break services. We know that with increased technology and medical expertise, more children with life limiting illnesses are living longer so there is and will continue to be an increasing demand for a greater range of respite services.

This proposal is part of a wider review of services to children with disabilities and complex physical health and social care needs. It is aimed at delivering a modernised service that ensures:

- Equitable access to services based on assessed need
- Safe and effective care
- Flexible and sustained provision
- Support networks for parents and carers, including access to suitable respite care

**Respite services we currently provide**

The Trust currently provides a range of respite services. We work in partnership with the voluntary and community sector, including the Northern Ireland Children’s Hospice in providing respite services. We also acknowledge the valuable contribution made by our approved host families who provide respite in their homes through our Sharing the Care Short Break Service.

The range of respite services includes:

- Residential based respite
- Family based respite
- Summer scheme provision
- Community activities
- Evening and weekend group activities
- After school activities
- Sponsored day care
Overnight care is also provided in the home, particularly for children with complex physical healthcare needs to enable parents to have a night’s rest. This type of care is similar to that provided within a hospital environment. There is an urgent need for us to provide respite for these children and families in addition to this essential support.

Currently 125 families receive respite services through the Sharing the Care Short Break Service for day and overnight care, with 55 families receiving respite through Whitehaven and 22 from Rainbow Lodge.

**How we propose to provide respite services in the future**

We believe that children and their families would benefit from a wider range of more flexible 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 units. This has meant that, on occasions, planned respite for children had to be cancelled. These safety concerns led to the temporary closure of Cherry Lodge in May 2013. At this point, respite services from within Cherry Lodge continue to be suspended 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 Unit 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 Unit.

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 unit in a central location in the Trust. 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. 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.

**Involving you**

We are committed to improving the way we provide services for to children with disabilities and complex physical health and social care needs so that children have equal access to services according to their assessed need and we need you to help us to do this. We believe that the people who use the service, their carers and communities and the staff who deliver the service are best placed to tell us what the new service should look like and we are keen to involve these groups specifically in the process.

**Impact on staff**

The principles of the Trust’s Management of Change Human Resource Framework provide a robust and transparent process for proposals that impact on our staff. The Trust has systems in place to support staff through the changes. A communication strategy will make sure that staff are kept fully informed of any proposed action and developments. Staff will also have regular communication meetings with their managers to discuss plans, influence the planning process and air their concerns. The Trust will work in partnership with trade unions to assess the impact on staff and to put robust mitigating measures in place.

**Promoting equality**

The Northern Trust is committed to promoting equality of opportunity, good relations and human rights in all aspects of its work. In keeping with our legislative requirements, the Trust has completed and is consulting on an Equality Impact Assessment (EQIA) on these proposals which is available on the Trust’s website at [http://www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)

**Tell us what you think**

We wish to consult as widely as possible on the proposals within this document and the findings of our Equality Impact Assessment over a 12 week period commencing 3 March 2014 and ending 26 May 2014.

This document is available, on request, in accessible formats, including Braille, CD, audio cassette and minority languages.

To facilitate you feedback, a consultation proforma is available on the Trust Website at [http://www.northerntrust.hscni.net](http://www.northerntrust.hscni.net). However we welcome your feedback in any format. Comments on all aspects of our proposals are welcome before 26 May 2014.
If you have any queries or comments regarding this consultation document or EQIA and its availability in alternative formats (including Braille, disk and audio cassette, and in minority languages to meet the needs of those who are not fluent in English) then please contact

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In compliance with the legislation, when making any final decision the Trust will take into account the feedback received from this consultation process. A consultation feedback report will be published on the Trust web site.

**Thank you for taking the time to read this document.**

[Signature]

Director Childrens services  
Exe. Director of Social work
Questions and answers

Why do we need to change our existing services?
We must ensure that services are available that can support the growing numbers of children with disabilities and their different needs, both now and in the future.

What is the possible timescale for these proposals?
We are consulting on our proposals for 12 weeks and the consultation process ends on 26 May 2014.

What services will be provided to replace the services in Cherry Lodge?
More flexible respite options will be provided to suit the changing needs of individual children and families. Overnight respite will continue to be provided for families from within Whitehaven Respite Unit, the Sharing the Care Short Break Service and Rainbow Lodge. Arrangements for those families who are supported within their own homes will not change.

What will happen to staff?
We value and respect our staff and will keep them informed at every stage. The principles of the Trust’s Management of Change Human Resource Framework provide a robust and transparent process for supporting staff through the change process.

I am concerned that any change to services will be detrimental to my child’s health?
The Trust has experience in sensitively managing changes with children and their families and every effort will be made to keep any disruption resulting in any change to an absolute minimum. The Trust will continue to fully engage with families and carers throughout this process and we will be guided by them on how best to meet the individual needs of their children.

What will happen to the views we provide – will they be considered by the Trust?
All the views gathered during this consultation will be considered before any final decisions are made. A consultation feedback report, detailing the feedback and how the Trust considered it, will be put on our website.