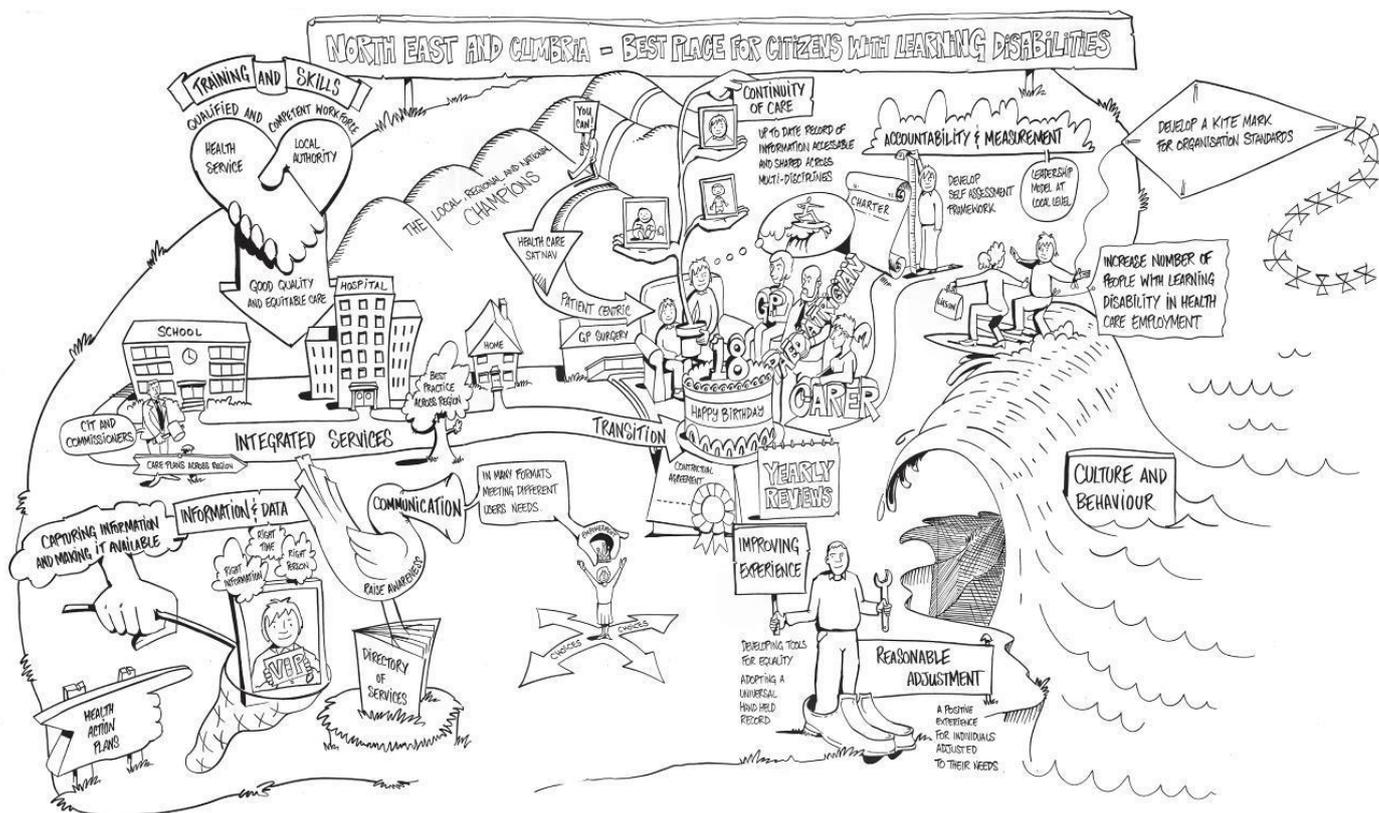


# Our Needs and Responsibilities

## Respite Services for People with Learning Disabilities and Complex Needs



December 2016

## **1. Introduction**

This document tells you about respite services that adults with learning disabilities and complex needs and their families and carers can use now. It also tells you about things that are happening in this area and across the country to make respite services better for everyone using them.

We are giving you this information to help you take part in discussions that are taking place in the Hartlepool, Stockton-on-Tees, Middlesbrough and Redcar and Cleveland areas. These discussions are being led by NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group and NHS South Tees Clinical Commissioning Group ('the CCGs').

CCGs are the organisations that buy and develop local health services, and make sure that health services meet the needs of local people now and in the future.

'Respite care' can mean different things to different people. We think that the role of respite is to give the carer, and the person being cared for, a break. This can happen in many different ways, depending on the needs of the people involved.

We are going to talk to people with learning disabilities and complex needs, their families and carers to help us understand what respite means to them.

## **2. What respite services do we have now?**

The main respite services in Teesside that are funded by the NHS are called 'bed-based' services. This is because people with learning disabilities and complex needs go to one of two buildings and stay overnight, or for a number of nights. Both of these services are run by Tees, Esk and Wear Valleys NHS Foundation Trust.

Day services are provided from a number of places, such as The Orchard in Middlesbrough, Kilton View in Brotton and Allensway in Stockton. The Orchard is provided by the local council with staff from health and the local council. Kilton and Allensway are provided by the local council, but are used by a lot of people who have joint funding from health and the local council.

All of these services are for adults living in Teesside with a learning disability and complex needs who also have health problems. These health problems include things like:

- Behaviour that challenges
- Mental health
- Severe autism
- Complex epilepsy

- Profound and multiple disabilities

At the moment there are five beds at Bankfields, which are accessed by 51 people with different needs. Aysgarth has 6 beds, which are accessed by 43 people. This includes people who have complex needs and those whose behaviour challenges services. Nearly half of the people who access respite at Bankfields or Aysgarth also access day services five days each week.

As well as respite services paid for by the NHS, some people use respite services paid for by their local council. Other people use respite services that are funded jointly by the NHS and the local council.

Some people now use personal health budgets. This is where people using respite services are allocated money by the NHS to choose and buy their own services. Different people have different respite needs, and personal health budgets give people the opportunity to decide which health respite services best meet their particular needs. As of 16<sup>th</sup> August 2016, 139 people in Middlesbrough, Redcar and Cleveland have taken up personal health budgets already. In Hartlepool and Stockton-on-Tees, 121 people have taken up personal health budgets.

Local councils provide a number of different respite and day opportunity services. Some of these are provided by the councils themselves, while the council pays private companies to provide others. For people who are assessed as having complex and eligible health needs their packages are either fully or part funded by the CCG. Some of those people access services that are commissioned / provided by the local council.

People who have social care needs can also access direct payments to meet their respite needs. This is where money is allocated to allow people to arrange holidays or other types of activity to best meet their needs.

We are now talking to people with learning disabilities and complex needs and their families and carers to help us understand their experience of using all of the different types of respite services. We also want to find out more about other things people do to meet their respite needs and how many people take part in different respite services or activities.

### **3. What's happening in our area?**

Middlesbrough, Redcar and Cleveland:

NHS South Tees Clinical Commissioning Group has a plan, called the '***Clear and Credible Plan 2012 – 17***', about how local health services should be run now, and how they should run in the future. Part of the plan is to make sure that the CCG listens to what is important to local people and takes this into account when it is buying new services or making changes to existing services. The plan also aims to get health and social care services to work more closely

together. One of the areas the plan will think about is services for people with learning disabilities and for carers.

Hartlepool and Stockton-on-Tees:

NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group also has a '***Clear and Credible Plan 2012 – 17.***' It looks at health inequalities and how these can be addressed by developing effective health services based in local communities to provide better care in the best place for people using the services. This will better meet the needs of patients and make sure that services provided are high quality.

Across Teesside:

***Personal Health Budgets*** is the name for money that is given to people with learning disabilities and their carers so that they can pay for a wide range of items and services, personal care and equipment. This helps people to have more choice and control over the type of health services they use and the way that they use them. The CCGs would like more people to be able to have personal health budgets so that they can have more control and choice over the type of health services they use.

#### **4. What's happening across the country?**

There is a project called ***Transforming Care*** that is working across the country. A really important part of this project is to look at how people with learning disabilities and their families and carers can use a bigger range of different types of services, closer to where they live.

Transforming Care is also focusing on making sure that services are planned and delivered to people in a way that meets their individual needs and helps them to be in control of the services that they receive. People can consider the option of being given some money to choose their own respite services and be able to choose how their needs are met.

Another important part of Transforming Care is about making sure that there is less reliance on services that are provided within inpatient settings. This is going to be done by making sure that there are good services available in the community.

The NHS has a plan about how the health service needs to change. This is called the ***Five Year Forward View***. The plan talks about how the health service needs to change and talk more to patients, carers and members of the public to help them do things to stay well. The NHS can do some things to change things, but it also wants to work more with local councils, employers and communities where people live.

The **Care Act** says that health and social care services should be more joined up and person-centred. This means that care and support should be based more on the person who needs them. The Care Act says that the NHS and local councils should work together to try and join up services.

The **NHS Act 2006** (including as amended by **the Health and Social Care Act 2012**) says that the NHS has to involve people when it buys or makes changes to local health services.

The **NHS Constitution** is a document that tells patients, members of the public and NHS staff about their rights and how they should be treated when they use NHS services. The NHS has to think about what the NHS constitution says when buying or making changes to health services.

## **5. Why do we think respite services could be better?**

The number of people who need to use respite services for people with learning disabilities and complex needs is getting bigger. There are also children and young people who will soon need to use respite services as they become adults. All of this is in addition to all the people that are already using respite services now.

There are also more people who have very complex needs. For this reason, some respite services find it hard to keep some people safe. We need to develop better links between health services and social care services that people are also using.

Some people who have behavior that is challenging need services that are just for them. This is because the needs of people with challenging behavior cannot always be met safely in services for people that don't have challenging behavior.

Respite services that we have now do not always meet the needs of people using them. For example some people may not benefit from social care services or the health respite services we have now. For some people there may be a gap in services as their needs are not met by existing health or social care respite services.

There are some people who use bed-based respite services and day services at the same time. There might be a better way to meet the needs of these people in a different way.

The Transforming Care agenda focusses on the personalisation of services for people to meet their individual needs and preferences. The emergence of personal health budgets to people with learning disabilities and complex needs supports this.

Current options available for people with learning disabilities and complex needs are limited. More innovative options need to be considered and developed for individuals to make sure their needs are met with the person truly at the centre of their own support. Children and young people with learning disabilities and complex needs who are reaching adulthood have different

expectations about options that should be available and need to receive services to appropriately meet their needs.

Currently transport between bed-based respite provision, day service facilities, day opportunity locations and home limit the options that might be available to people. It is hoped that the period of initial engagement will help us think about this and suggest ways it can be addressed in the future.

The information we have shows that there are people with a wide range of needs who are accessing services for people with learning disabilities and complex needs. Work needs to be done to better understand this and to develop assessment to ensure that resources are allocated fairly and in response to the needs of the individual and their carer.

## **6. What do we think respite services should be like in the future?**

We have thought about everything that is happening locally and across the country that we have talked about in this document. We think that respite services for the future should be:

- Developed in partnership with people with learning disabilities and complex needs, their families and carers
- Safe and based on the needs of each person using them
- Diverse enough to meet the needs and preferences of individuals
- Available to people on a needs-led basis and available at the right time
- Available within local communities and close to where people live
- Flexible and responsive

It is important to understand the views of the local population in relation to these principles and also to obtain ideas about how we can make this happen.

## **7. What are we going to do now?**

We recognise that we have already spoken to people with learning disabilities and complex needs, their families and carers in 2015. However, we think it is important to talk to people again to build on the previous engagement and to help us understand the bigger picture from a bigger cross-section of people.

From December 2016 to the end of February 2017, the CCGs, working in partnership with the 4 local councils, will be talking to people about:

- What respite means to them
- What it's like to use respite services
- What is good about the respite services we have now?
- What is not so good about the respite services we have now?
- How we can make sure that the needs of people who have learning disabilities and complex needs are met in future

What people tell us will be added to the feedback we already have from 2015 to help us think about whether we need to make changes to respite services to make them better for the future.

If we think that we may need to make a lot of changes, we will give people who use respite services and the public the opportunity to tell us what they think about them before we decide what changes to make.