

# Case for Change

*Respite Opportunities and Short Breaks for  
People with Complex Needs and Learning  
Disabilities and/or Autism*

*NHS Hartlepool and Stockton-on-Tees CCG  
and  
NHS South Tees CCG*

# 1. Executive Summary

The national Transforming Care Programme and the NHS Five Year Forward View includes a strong emphasis on personalised care and support planning, personal budgets and personal health budgets to put people at the centre of their care to enable maximum choice and control about how needs are met.

There is a need to improve services outside hospitals, ensuring that they are effective, resilient and flexible to support and facilitate timely discharge from inpatient settings and to prevent unnecessary admissions to such facilities.

The Five Year Forward View focuses on breaking down the barriers in how care is provided between family doctors and hospitals, between physical and mental health and also between health and social care.

The Care Act 2014 strengthens Local Authority and Clinical Commissioning Group obligations to carers to ensure that they are supported in their roles.

NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group (HaST CCG) and NHS South Tees Clinical Commissioning Group (STCCG) are responsible for commissioning the majority of local health services to meet the needs of the local population. This report will refer to the Clinical Commissioning Groups (CCGs), collectively as appropriate, throughout this report. The CCGs' Clear and Credible Plans 2012 – 2017 set out a series of priorities, one of which relates to provision of services for patients with learning disabilities. The challenges faced by increasing demand for appropriate services to meet the needs of individuals are well established nationally and locally. In order to tackle these challenges, whilst continuing to commission good quality and appropriate services, it will be important to work collaboratively with our local health and social care partners.

This document describes the respite services currently available for adults with learning disabilities and complex needs and outlines drivers for change. It is intended as a discussion document to support the development of local services to meet the current and future needs of the local population, which can effectively respond to the changing environment.

The respite review project has analysed information from NHS services and Local Authority. Findings indicate the following:

## **Demand is growing**

As is seen nationally, demand is growing for robust, responsive and local community based services for people with learning disabilities and complex needs, which includes respite provision.

The information we have indicates that there are a number of children and young people who will have eligible needs into adulthood adding to the current number of people who access respite services.

## **The complexity of need is increasing**

Information available from Local Authorities and current service providers, that provide services to people with Learning Disabilities and complex needs, identifies that the

needs of the individuals are extremely complex. Some services find it difficult to meet the changing needs of individuals appropriately and there is a need for services for people with learning disabilities and complex health needs which complements and supports any other social care provision that they may access.

Further to this, there is an identified need for services to therapeutically meet needs of people whose behaviour is described as challenging that cannot be safely or appropriately met in other service provision.

### **There are potential gaps**

Information available at this time indicates there is a gap in services available for people whose needs are not being met appropriately in social care services but whose needs are not appropriate for the bed based and day service facilities currently available under NHS commissioned services.

### **There is potential duplication**

There are some people who access health funded bed based respite in addition to traditional day service opportunities, where it could be considered that provision is being paid for twice when the individual is accessing bed based respite provision. The needs of these individual's may be able to be met better, in a different way.

### **National and local policies influence operational delivery**

The Transforming Care agenda focuses 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.

Work will be required to ensure that patients and carers understand, and are engaged with, the option of personal health budgets and that there are a range of innovative and specialist services available within the market place for people to purchase with personal health budgets. It is important that sustainable services are available to facilitate the personal health budget agenda.

### **Availability of choice needs to improve**

Current options available for people with learning disabilities and complex needs are limited and more innovative options need to be considered and developed for individuals in order that their needs are met in a holistic way with the person truly at the centre of their 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.

### **Cost effective and appropriate transport options need to be made available**

Currently transport between bed based respite provision, day service facilities, day opportunity locations and home poses some significant issues in relation to the options that might be available to individuals.

The associated costs and benefit contributions for transport and mobility need to be considered. It is hoped that the period of initial engagement will support in understanding the complexities of this and suggest ways that this can be addressed in the future.

### **Access to and allocation of service provision needs to be effective**

The information available demonstrates that there are people with wide ranging needs who are accessing services for people with learning disabilities with complex needs. Work needs to be done to better understand this and to develop appropriate and responsive systems of assessment and allocation to ensure that resources are allocated fairly and in response to the needs of the individual patient and their carer.

The review focussed on health respite services for people with learning disabilities and complex needs in the CCG areas. This is to ensure that these services will appropriately meet the needs of the population now and into the future.

The CCGs continue to work in partnership with the four Local Authorities across the CCG areas to ensure that the review considers the services available for people with complex health and social care needs.

## **2. Service Outline**

### **2.1. Current Services**

#### **Local respite services**

The term 'respite' means different things to different people and is the subject of much debate. Informal patient and carer engagement will support the programme to better define this and refine appropriate provision.

The role of respite is to provide a break for the person who is being cared for. The common understanding is that the respite break must be of mutual benefit for the person and for their main carers and is usually an intervention or service which is taken outside of the family home. This has been consolidated by the engagement activities where the perception is that the respite for the carer must mean that they are receiving a total break from their caring responsibilities and where people can go where they will be in a safe place with trusted and known staff.

As a point of law, respite care is provided under community care legislation rather than carers legislation and as such is defined as a service for the person who is cared for rather than the carer. It is suggested by a charitable organisation that The Care Act 2014 means that replacement (respite) care is now recognised as a service to the person who is cared for.

#### **CCG commissioned services**

Health funded respite services for people with learning disabilities and complex needs in Teesside are currently primarily buildings based. The adult bed based respite service is centred on two specialist respite services provided by Tees Esk and Wear Valleys NHS Foundation Trust (TEWV).

In Tees, bed based respite services for adults with learning disabilities and complex needs are delivered from Aysgarth Short Term Care Unit (6 beds) at 163 Durham Road, Stockton, TS19 0EA and Unit 2 Bankfields Court (5 beds) at Normanby, Middlesbrough, TS6 0NO.

Access to the bed based facilities is managed directly by the service provider who currently manages the assessment and allocation process.

There are two day services facilities which operate Monday to Friday based in Middlesbrough (Orchard) and the other in Brotton (Kilton View). These schemes are provided jointly between the Local Councils and TEWV and as such are staffed by health and social care staff and are able to meet the needs of people with extremely complex or challenging needs.

The bed based services and these day service facilities work interdependently to meet the complex needs of the people who access the services.

The services aim to provide respite services to adults living in Teesside with a Learning Disability and associated complex needs who require additional health intervention or assessment which may exclude them from mainstream services and life opportunities due to:

- Behaviour that challenges services
- Mental health (dual) diagnosis
- Severe autism
- Complex epilepsy
- Profound and multiple disabilities

Comprehensive information about the needs of the people who access the bed based services and day services facilities have been provided and has been analysed. Work has been undertaken to identify those people whose needs can only be met in a clinical environment with the input of clinical and professionally qualified staff.

The bed based services currently operate an open referral system without the need for formal professional referral and there is a basic assessment and eligibility criteria identified and process in place. The assessment is multidisciplinary and seeks views from many professionals engaged in each individual's support network. The assessment tool includes a series of domains for consideration including communication, behaviour, epilepsy, self-care skills and other appropriate domains.

The assessment tool identifies an eligible health need and whether an individual was suitable to receive overnight respite services. There is no consideration of the needs of the carer in relation to the amount of respite that is offered. If the person is identified as eligible to receive health respite then they will be offered an equivalent amount to everyone else already within the service. There is commitment from the provider to develop the assessment and allocations procedure to be more focussed around the needs of the individual and their carer(s).

Emergency provision is accommodated within the core set up within both services which may result in late changes to the booked respite stays.

Both the bed based services and the day services are staffed by clinically qualified staff, health care assistants, and ancillary staff.

Other than the services provided by TEWV, there are no other NHS commissioned respite provisions for people with learning disabilities and complex needs.

Some individuals, with either fully funded continuing health care packages or where packages are jointly funded by CCGs and the Local Authorities, receive respite through Local Authority commissioning arrangements, where the needs of the individuals are met in this way. These individuals may require access to health respite services in the future.

As of 16<sup>th</sup> August 2016, 139 individuals in South Tees and 121 in Hartlepool and Stockton-on-Tees with learning disabilities have taken up personal health budgets already.

Information available confirms that individuals who take personal health budgets and/or direct payments from Local Authorities use their resources to do a wide variety of activities including:

- Take holidays in specially adapted caravans or in other locations either with a team of support or with Parent Carers,
- Access a variety of different venues and community activities,
- Employ Personal Assistants.

### **Current activity and utilisation of CCG commissioned services:**

Work has been undertaken to understand the capacity and activity within the bed based and day service provision provided by TEWV. Business Intelligence Officers have undertaken analysis of the information in consideration of capacity, activity, utilisation and links to identified needs and prevalence of conditions. The analysis also captures information about emergency provision and where additional nights have been utilised and is summarised below.

### **Aysgarth**

There are 6 beds at Aysgarth which, as at 31<sup>st</sup> May 2016, are accessed by 43 people whose needs also vary in terms of complexity. The facilities at Aysgarth mean that a range of individuals can be accommodated and supported at the same time. Day service opportunities for people who access Aysgarth are usually provided through the Local Authority day service provision at Allensway. Information available confirms that occupancy in the unit (based on 6 beds) is usually between 60 and 70% which rose as high as 78% in July 2012 and was as low as 51% in August 13.

Nearly 90% of the people who access overnights at Aysgarth are people from the Stockton-on-Tees locality, only 6 of the people who have accessed the service since 2012 have come from outside of this geographic boundary. It is noted that individuals from Hartlepool use a wider variety of community services and arrangements through the Local Authority or through direct payments to meet respite needs, even for those people with Continuing Health Care funding or through joint package arrangements.

On average, each individual is admitted 10 times each financial year, with the highest recorded number of admissions in any one year as 26 times. The average number of nights for each of these individuals is 39.

Between 1<sup>st</sup> April 2012 and 31<sup>st</sup> May 2016 there have been 106 admissions recorded that were not planned respite, of these 50 were categorised as 'emergency' admissions to the service. Reasons for emergency admissions to Aysgarth (or extensions to the length of stay for an individual) include the following (in order of prevalence – greatest first):

- Carer unwell (including falls and post-operative recovery for the carer(s))
- Carer/family breakdown (including family illness)

- Carer medical treatment or hospitalisation
- Deterioration in health (including mental health) for the person
- Home repairs or unsuitable equipment at home
- Post-operative recovery for the person
- Carer to attend funeral

Nearly 50% of the people who access overnights at Aysgarth have been with the service(s) for 5 years or more. This demonstrates that there are a large number of individuals who have long relationships with the services and who are very dependent on the services. The group of people who use the services remains fairly static with only a small number of new referrals each year.

## **2, Bankfields Court**

Information available at this time shows that there are five beds at 2, Bankfields Court, which as at 31<sup>st</sup> May 2016, are accessed by 51 people whose needs vary significantly. The model of operation here means that the unit splits the available weeks to ensure that they can offer dedicated resources to people who have complex needs and to those who have needs or behaviours that challenge services. The building itself could not accommodate people complex needs at the same time as someone who presents in a way that is challenging to the service.

Nearly half of the people who access bed based respite at 2, Bankfields Court also access day services at the Orchard or at Kilton View and most access these day services five days each week. In order to operate a flexible and responsive service to all patients, there are occasions where the service utilises space in an adjacent building in order to increase the space available, the capacity of the service is not increased and at no point are there more than 5 beds booked (since January 2015). Information available confirms that occupancy in the unit (based on 5 beds since January 2015) is usually between 80 and 90% but was as low as 70% in December 15.

Over 90% of the people who stays overnight at 2, Bankfields Court are people from the Middlesbrough and Redcar-Cleveland localities. Only 5 of the people who have accessed the service since 2012 have come from outside of this geographic boundary.

On average, each individual stays overnight 7 times each year, with the highest recorded number of admissions in any one year is 19 times. The average number of nights for each of these individuals is 32.

Between 1<sup>st</sup> April 2012 and 31<sup>st</sup> May 2016 there have been 115 admissions to the service not through planned respite, of these, 39 were categorised as 'emergency' admissions to the service. Reasons for emergency admissions to 2, Bankfields Court (or extensions to the length of stay for an individual) include the following (in order of prevalence – greatest first)

- Carer unwell (including falls and post-operative recovery for the carer(s))
- Carer/family breakdown (including family illness)
- Carer medical treatment or hospitalisation
- Bereavement in the family
- Rehabilitation/transition for the person
- Safeguarding

Nearly 50% of the people who access overnights at 2, Bankfields Court have been within the service(s) for 5 years or more. This demonstrates that there is a large cohort of individuals who have long relationships with the services and who are very dependent on the services. The group of people who use the services remains fairly static with only a small number of new referrals each year.

**Baysdale (not included as part of the consultation)**

Baysdale is a 6 bedded short term care unit at Roseberry Park for children and young people with learning disabilities and complex needs. As at 31<sup>st</sup> May 2016, there were 10 individuals aged 14 years and above who have not yet been discharged from the service. It is likely that once these individuals reach adulthood, they will seek to receive overnight and bed based respite services to meet their individual needs.

Children and young people aged 14+ years occupy between 10 and 30% of the available capacity within the unit in any given month despite representing a significantly smaller proportion of all the children and young people (all ages) who access the service.

Work has been undertaken to understand the needs and the co-morbidities of the individuals who access the service at Baysdale and we can draw conclusions about the future needs of individuals who will require respite services in the future. It is noted that prevalent needs include medication administration, bathing and personal hygiene and communication needs. More detailed analysis of these domains has been undertaken in relation to gender split for the prevalent needs domains. The findings of this analysis are supported by details provided by the TEWV Transitions Nurses.

**The Orchard and Kilton View Day Services (not included as part of the consultation)**

There are a maximum number of 36 day places each day at The Orchard and 18 per day at Kilton View. As at 28<sup>th</sup> August 2016 there were 40 individuals who were accessing The Orchard and 15 who access Kilton View. Since this time the numbers have decreased slightly and information has been extracted about a combined total of 53 individuals who access the service.

The table below describes the services, the level and complexity of need and details about how the service is delivered within each setting.

	The Orchard, Middlesbrough	Kilton View, Brotton
Service delivery.	<p>There is a maximum occupancy of 36 people per day. In addition the level of support will influence final numbers in order to ensure safe delivery of the services.</p> <p>The service is to be made available to individuals:</p> <ul style="list-style-type: none"> <li>• Aged 16 – 65,</li> <li>• Live within Middlesbrough area,</li> <li>• Diagnosed with a learning disability or physical</li> </ul>	<p>There is a maximum occupancy of 18 people per day. In addition the level of support will influence final numbers in order to ensure safe delivery of the services.</p> <p>The service is to be made available to individuals:</p> <ul style="list-style-type: none"> <li>• Aged 16 – 65,</li> <li>• Live within Redcar and Cleveland</li> <li>• Diagnosed with a learning</li> </ul>

	<p>disability,</p> <ul style="list-style-type: none"> <li>• Who have undergone a Social Care Assessment and a Community Nursing Assessment, which has identified needs which could be met by the service,</li> <li>• Who have completed the eligibility checklist for the service</li> </ul>	<p>disability or physical disability,</p> <ul style="list-style-type: none"> <li>• Who have undergone a Social Care Assessment and a Community Nursing Assessment, which has identified needs which could be met by the service,</li> <li>• Who have completed the eligibility checklist for the service</li> </ul>
<p>Overview of needs met (include overview of client group and range of needs)</p>	<p>The service provides day services to people with a severe learning disability and associated profound physical and complex care needs. The service works in partnership with Local Authorities of Middlesbrough and Redcar and Cleveland to meet of people with complex health presentations.</p> <p>The service aims to ensure the profound physical needs of the service users are met and their physical and emotional safety is ensured whilst involving them in a stimulating and varied range of activities, both within the service and their local communities.</p> <p>Such work largely involves skill in developing long-term relationships with service users with very limited conventional communication repertoire and being sensitive to and interpreting their presentation and symptoms which may be shadowed by the complexity of their condition.</p>	<p>Kilton View provides day services to people from Redcar and Cleveland locality with a severe learning disability and associated profound physical and complex care needs.</p> <p>The service aims to ensure the profound physical needs of the service users are met and their physical and emotional safety is ensured whilst involving them in a stimulating and varied range of activities, both within the service and their local communities.</p> <p>Such work largely involves skill in developing long-term relationships with service users with very limited conventional communication repertoire and being sensitive to and interpreting their presentation and symptoms which may be shadowed by the complexity of their condition.</p>
<p>Hours/days of operation</p>	<p>The service is delivered 8.30-4.30 Monday to Friday (excluding Bank Holidays)</p>	<p>The service is delivered 8.30-4.30 Monday to Friday (excluding Bank Holidays)</p>
<p>On-site activities provided</p>	<p><b>Interventions</b> Appropriate pathways will be identified to manage the provision of appropriate interventions. A range of therapeutic interventions are provided including:</p> <ul style="list-style-type: none"> <li>• Psychological – sound therapy, relaxation, stress management training – linked to Mood.</li> </ul>	<p><b>Interventions</b> Appropriate pathways will be identified to manage the provision of appropriate interventions. A range of therapeutic interventions are provided including:</p> <ul style="list-style-type: none"> <li>• Psychological – sound therapy, relaxation, stress management training – linked to Mood.</li> </ul>

	<p>Interest and Pleasure Questionnaire (MIPQ) as part of the Profound and Multiple Learning Disabilities pathway.</p> <ul style="list-style-type: none"> <li>• Social inclusion promoting use of existing community facilities, leisure activities such as attending sports events</li> <li>• Emotional – verbal and non-verbal day-to-day support to clients who require in-depth knowledge of their presentation from staff to interpret their feelings and potential distress relaxation. Use of the Mood. Interest and Pleasure Questionnaire assessment. Mood boosting activities e.g. music therapy</li> <li>• Physical including dietary intake, postural care, chest care, Percutaneous Endoscopic Gastrostomy (PEG), hydrotherapy, measurement of expressed pain (DISTAT)</li> <li>• Educational – skills training, communication methods, use of touch screen for educational software</li> </ul> <p>These are delivered by fully trained staff including nurses, occupational therapists, support workers, psychologists, physiotherapists and speech/language therapists with medical input where necessary. Frequency of interventions is dictated by the care plan.</p> <p><b>Health Promotion Activities</b> These activities are contained within each person’s Health Action Plan and include:</p> <ul style="list-style-type: none"> <li>• Medication</li> <li>• Diet/fluid</li> <li>• Exercise</li> <li>• Breathing</li> <li>• Health screening</li> <li>• Elimination</li> <li>• Managing complex needs</li> </ul>	<p>Interest and Pleasure Questionnaire (MIPQ) as part of the Profound and Multiple Learning Disabilities pathway.</p> <ul style="list-style-type: none"> <li>• Social inclusion promoting use of existing community facilities, leisure activities such as attending sports events</li> <li>• Emotional – verbal and non-verbal day-to-day support to clients who require in-depth knowledge of their presentation from staff to interpret their feelings and potential distress relaxation. Use of the Mood. Interest and Pleasure Questionnaire assessment. Mood boosting activities e.g. music therapy</li> <li>• Physical including dietary intake, postural care, chest care, Percutaneous Endoscopic Gastrostomy (PEG), hydrotherapy, measurement of expressed pain (DISTAT)</li> <li>• Educational – skills training, communication methods, use of touch screen for educational software</li> </ul> <p>These are delivered by fully trained staff including nurses, occupational therapists, support workers, psychologists, physiotherapists and speech/language therapists with medical input where necessary. Frequency of interventions is dictated by the care plan.</p> <p><b>Health Promotion Activities</b> These activities are contained within each person’s Health Action Plan and include:</p> <ul style="list-style-type: none"> <li>• Medication</li> <li>• Diet/fluid</li> <li>• Exercise</li> <li>• Breathing</li> <li>• Health screening</li> <li>• Elimination</li> <li>• Managing complex needs</li> </ul>
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	<p>through pathway</p> <p>The service has links to multi-disciplinary advice and interventions through the community teams.</p> <p><b>Training Activities</b> Identified training needs of service users are incorporated into the assessment and care planning process. Skills are developed at a very basic skill level relevant to the needs and abilities of the service user. Specific training sessions are, for example:</p> <ul style="list-style-type: none"> <li>• Cookery skills</li> <li>• Use of technology i.e. using a large computer touch screen</li> <li>• Hand / eye co-ordination using games and sports activity</li> <li>• Communication skills</li> <li>• Sensory skill development</li> </ul>	<p>through pathway</p> <p>The service has links to multi-disciplinary advice and interventions through the community teams.</p> <p><b>Training Activities</b> Identified training needs of service users are incorporated into the assessment and care planning process. Skills are developed at a very basic skill level relevant to the needs and abilities of the service user. Specific training sessions are, for example:</p> <ul style="list-style-type: none"> <li>• Cookery skills</li> <li>• Use of technology i.e. using a large computer touch screen</li> <li>• Hand / eye co-ordination using games and sports activity</li> <li>• Communication skills</li> <li>• Sensory skill development</li> </ul>
Off-site activities provided	<ul style="list-style-type: none"> <li>• Social inclusion promoting use of existing community facilities, leisure activities such as attending sports events</li> <li>• hydrotherapy</li> <li>• eating out</li> <li>• visits to museums and exhibitions</li> <li>• specialist sports groups</li> </ul>	<ul style="list-style-type: none"> <li>• Social inclusion promoting use of existing community facilities, leisure activities such as attending sports events</li> <li>• hydrotherapy</li> <li>• eating out</li> <li>• visits to museums and exhibitions</li> <li>• specialist sports groups</li> </ul>
Transport arrangements to and from the centre	Local Authority transport Own transport NHS Patient Transport Services	TEWV Kilton View's mini buses. Local Authority transport Own transport
Transport arrangements for off-site activities	LA transport	TEWV Kilton View's mini buses.

Analysis has been undertaken in relation to the health and social care day services provided at the Orchard and Kilton View day services. There is a combined total of 53 individuals who access services at either day service. Of these 53, 24 (45%) also access bed based respite at 2, Bankfields Court, Normanby. Nearly 90% of the people who access the day services present with complex needs rather than challenging needs.

Information available indicates that most people accessing the day services and who do not receive overnight respite at 2, Bankfields Court (or Aysgarth) are Local Authority

funded; there are a similar number of individuals who are either Continuing Health Care funded or who have joint packages. The vast majority of these individuals are reliant on day service transport, LA transport or their own transport. There is one individual who uses an ambulance.

The majority of individuals who do receive overnight respite at 2, Bankfields Court as well as accessing day services at the Orchard or Kilton View are in receipt of Continuing Health Care funding or joint package funding arrangement. The majority of these individuals are reliant on transport provided by the Local Authority.

Analysis has been undertaken in relation to the identified needs (initial assessment scores and categories) and funding arrangements for individuals who can be cross referenced between the bed based services at 2, Bankfields Court and day services at Kilton View or the Orchard i.e. because they access bed based respite as well as day service provision. The findings indicate that the majority of people who access bed based respite in addition to day services at either 2, Bankfields Court or Kilton View have jointly funded packages with the Local Authority.

The assessment profiling tool that is used to assess suitability for the day services differs from the assessment tool that is used for 2, Bankfields Court. At times this has presented conflicting information about the profundity of needs for an individual.

Of those individuals who receive overnight support at 2, Bankfields Court as well as day services at the Orchard or Kilton View, nearly 80% of them access the day services on a five days per week basis.

Work has been undertaken to understand the needs and the co-morbidities of the individuals who access the day services and we can draw conclusions about the typical needs for individuals who require respite provision. It is noted that prevalent needs include medication administration, daily living, bathing and personal hygiene, epilepsy and clinical intervention at mealtimes.

#### **Local Authority commissioned services:**

Local Authorities provide a range of commissioned respite and day opportunity services provided in house or by private sector providers, some of which are accessed by people with learning disabilities and complex needs where appropriate and their needs can be met appropriately within services. For people who are assessed as having complex and eligible health needs their packages are either fully or part funded by the CCG and who access services that are commissioned / provided by the Local Authority.

Direct payments are also made available to individuals with health and social care needs, who wish to do something different to meet their respite needs. Examples of this include direct payments to pay for holidays or alternative activities. Information continues to be gathered in order to obtain a full picture about the opportunities that are available and to understand typical uptake and quantify the numbers of people who access this option and the capacity available within these services. It is hoped that informal engagement with patients and their carers will support with our understanding of this.

Activity information for the services commissioned directly by Local Authorities was not easy to obtain and detailed analysis has only been possible in the case of one of the bed based respite units in South Tees area.

Local Authority colleagues have provided anecdotal information about percentage occupancy and number of clients (adults) accessing Local Authority commissioned bed based provision for respite.

- Hartlepool Borough Council has 23 clients accessing a 6 bedded facility (6 respite beds and 1 emergency bed) commissioned from a private sector provider, which has average approximate occupancy of 80%.
- Stockton Borough Council has approximately 80 clients accessing an 11 bedded facility, provided directly by the Local Authority, which has an average occupancy of 84% (between Jan and August 16).
- Middlesbrough Council provides overnight respite at an 8 bedded respite facility. Information gathered identifies that there are up to 50 distinct individuals who access these beds. Occupancy fluctuates on a night to night basis. However, the average occupancy in the setting is approximately 75%
- Redcar and Cleveland Borough Council provides overnight respite at a 5 bedded facility. Information gathered demonstrates that activity fluctuates. However, there is a significantly lower total overall percentage occupancy within the service in comparison with the CCG commissioned services. Average monthly occupancy is in the region of 50%. There are 36 distinct individuals who access the service and it is noted that it is not often than any one individual has more than 10 overnights in any one month. However the range of numbers of potential overnights within the service in a projected 12 month period ranges between 2 nights and 89 nights. There are often a number of cancelled bookings in each month and evident fluctuation in what is delivered to individuals. The end of the week /weekend periods has had the majority of total occupied bed days.

Other information available has enabled consideration around emergency provision within the Local Authorities.

## **2.2. Case for Change**

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 for people with learning disabilities and complex needs supports this. People have said that there is a need to ensure that people get the support that they need to manage personal budgets and still create opportunities for people to access different types of service even if they do not want to take personal budget payments.

In order to comply with national and regional health policy developments such as Transforming Care and the Care Act it is necessary to ensure that services available are community based and flexible in response to the identified needs of individuals and that their family carers are supported to maintain their own health and wellbeing as well as being able to maintain their caring role.

There is a need for the CCGs to deliver respite services for people with eligible health needs in a different, more effective way to ensure that the needs of individuals are met safely and in a way that meets the wide ranging and personalised outcomes for individuals and their family carers. Currently the offer for people with complex needs is limited and people have told us as part of the initial consultation that although they value the current services hugely, that there is not enough choice or flexibility.

It is important that the CCGs continue to make available necessary resources to ensure that the eligible health needs of individuals are met alongside any social care needs that they have which are being supported by Local Authorities.

Consideration is to be given to making changes to how services are delivered to increase the choice and flexibility offered to individuals and to their family carers.

By commissioning and delivering services in a different way individuals should receive personalised and appropriate support to meet individual assessed needs in a way that promotes positive outcomes for the individuals and for their family carers.

Developing service delivery options promotes the health and wellbeing of the patients and of their family carers and supports in the reduction of health inequalities that may exist for the patients who access respite provision through widening the available opportunities and meeting needs in a flexible and responsive way.

A variety of flexible and responsive services are to be considered which meet the identified respite needs of the individuals who access respite services now or who may do in the future.

Changing how respite services are delivered should remove uncertainty around sustainability and suitability of the services in their current format. This also allows for consideration of how the needs of the current and future populations will be met. Consideration needs to be given to how people's needs can be met to ensure that they have the best opportunity to achieve personal outcomes.

The number of people who need to use respite services for people with learning disabilities and complex needs is increasing. Children and young people will soon need to use respite services as they become adults and they often have different ideas about what respite opportunities and other options should be available to appropriately meet their needs. People have told us as part of the initial engagement activities that a wide range of creative opportunities and different choices need to be available to meet the diverse needs of the people coming through transitions.

There is also an increase in numbers of people who have very complex needs who need to be able to access robust and resilient services in the community. For this reason, some respite services find it difficult to keep some people safe. There is a need to develop better links between health services and social care services. People have said that it is important that there is enough staff with the skills and competencies required to respond to changes in need.

Some people who present behaviour that challenges services need provision that is tailored to them. This is because the needs of these individuals cannot always be met safely in services that provide support to people who have complex needs or for people whose needs don't challenge services in the same way.

Current respite services do not always meet the needs of the people using them or who may need to use them in the future. Some people's needs could be met in a different way to get better outcomes. The initial engagement activities tell us that people have said that there needs to be more choice and flexibility in services available for people with complex needs. This could mean that people could pick and mix the support they receive to meet their needs.

For some people, there may be a gap in services, as their needs are not met by existing health or social care respite services. For other people emergency situations mean that their respite stays are disrupted or in some cases emergency care and support has not been easily available. People who participated in the initial engagement activities have said that there needs to be a range of responsive options available for planned and emergency respite needs.

There are some people who use bed based respite services and day services at the same time. This duplication is costly to the NHS.

Current options available for people with learning disabilities and complex needs are limited. People have said that there needs to be more choice and better facilities for people with complex needs. 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.

Currently transport between bed based respite provision, day service facilities, day opportunity locations and home limit the options that might be available to people. People have said that transport arrangements need to be improved.

Available information indicates that there are people with a wide range of needs accessing services. People have said that it is important to have flexible and responsive services to meet the personal needs and preferences of the people who use them and to meet the individual needs of the family carer(s) and that systems need to be fair. Systems are being considered and developed to ensure resources are fairly allocated according to eligibility and assessment of need.

### **2.3. Future State**

The key issues that have led to this review and consideration of the development of services are as follows:

- Demand is growing
- The complexity of need is increasing
- There are potential gaps
- There is potential duplication
- National and local policies influence operational delivery
- Availability of choice needs to improve
- Cost effective and appropriate transport options need to be made available

- Access to and allocation of service provision needs to be effective and equitable

Developing the offer would ensure that there is more choice for individuals whilst still meeting their needs to feel and to be safe and to enjoy their respite experiences whilst the needs of their parents and carers are also being met.

Feedback from engagement and from research demonstrate the need for more choice and alternative options in addition to bed based provision to enable people and their families to mix and match the services that are needed to meet individual needs. Overnight provision in a buildings based facility has its place but that this isn't necessarily always the right option to provide respite which is so desperately needed.

Models of operation in other parts of the country make use of bed based provision and availability of other options such as personal support teams and community based workers which are purchased through Local Authority commissioning arrangements and/or by means of resource allocation and direct payments.

More cohesive working with CHC colleagues will be required in relation to assessment and allocation of provision/resources and for case management to support people to plan their respite services. It will be required to build in dynamic provisions into the contracting arrangements to enable individuals who have taken Personal Health Budget option to access services to ensure that there are no double funding arrangements for individuals who access the service(s).

### **2.3.1 Service Model**

Services/resources need to be available for all individuals who have learning disabilities and complex eligible health needs and who reside in the Hartlepool, Stockton-on-Tees, Middlesbrough and Redcar and Cleveland areas.

In order to support the Transforming Care agenda it is important that services/resources are made available close to the person's home to avoid lengthy and unnecessary journeys and that community services are robust and coherent enough to support people to remain in their own homes and to facilitate timely discharge back into the community where there has been inpatient admission.

Respite provision needs to be flexible and responsive to ensure that the changing needs of the individuals and their carers can be accommodated, which includes appropriate, safe and effective emergency provision as well as respite opportunities that can be routine and booked in advance.

Physical provision of bed based services would need to be located so that individuals who require it can access facilities within reasonable distance of their home.

Outreach and /or community provision could be a team of staff with clinical oversight as necessary that works out into people's homes to provide respite on a flexible basis or could support the person to access community facilities and holiday or short break options in suitable accommodation wherever the person chooses. The indication is that there is capacity and capability in the market to support varied respite options.

A menu of options is being developed which identify a unit price for each of the various options which can be built in to the packages of support and notional resource allocation.

The menu of options could include the following services/activities:

Overnight bed based care	Residential/nursing care home Setting
	Shared Lives placements
	Alternative accommodation - e.g. specially adapted residential accommodation, flats or houses
Support into own home	Support providers
	Outreach provision with clinical oversight
One to one or shared support to access community settings	Support providers
	Outreach provision with clinical oversight as required – tiered support approach
Holiday/Short break options (with or without natural support)	Alternative accommodation
	Chalet or caravan provision – specially adapted
	Hotel/guest house/bed and breakfast – as per preference of the individual
Flexible community based leisure and activity options	Farm/horticulture sessions
	Art and craft sessions
	Drama sessions
	Sensory/therapeutic sessions
	Sporting/active sessions
	Social events/sessions
Flexible community based day service options (with or without natural or paid for support)	Extended (7 day and late night) opening and availability
Transport	Could be provided as part of the services available (at a defined cost)
	Purchased separately on a journey by journey basis

Bed based and outreach support service(s) would need to be available throughout each and every 24 hour period and potentially be available 365 days each year. Other service(s) would need to be available on a 7 day flexible basis and be able to operate extended hours as per the needs of each individual.

Packages of support need to be developed around the individuals, requiring cohesive working between CCG, Continuing Health Care and Local Authority colleagues in relation to assessment and allocation of provision/resources.

Flexibility in the contracting arrangements will be required to enable individuals who have taken Personal Health Budget (or notional resource allocation) option to access services to ensure that there are no double funding arrangements for individuals who access the service(s) where any services are commissioned as a core service.

A predetermined assessment and allocations criteria is proposed which is based around notional resource allocation based on the respite needs of the individual and their parent or family carer.

## **2.3.2 Referral and access to the service**

A revised access and eligibility criteria will be developed that complements the Continuing Health Care assessment processes. A set of values and principles and draft assessment and allocations tool are currently being jointly developed with the current provider of bed based services.

Consideration will also be given to the needs of carers and what support provisions already exist within their own packages of support. This has been considered within the values and principles that underpin the assessment and allocations processes.

## **2.3.3 Care pathway and interdependencies**

There are numerous services that have direct interfaces with NHS respite provision. This has been evidenced in the information that has been received from various sources as well as the findings from engagement activities.

The key interdependencies are the NHS bed based provisions and NHS and Local Authority day centre and other respite provision. Transport is also a key consideration.

## **3. National context and evidence base**

### **National Context:**

#### **Transforming Care**

The focus of this national agenda is to ensure that people are supported to remain in the community and to reduce the unnecessary admission to inpatient facilities. A large part of this is to co-design and implement an effective, responsive, proactive, resilient and flexible community model of services and support to facilitate timely discharge and prevent admission to inpatient facilities. This is also supported by the principles that are outlined within the October 15 NHS England publication 'Building the Right Support'.

Transforming Care includes a strong emphasis on reduced reliance on bed based inpatient provision and the availability of community services within local communities, personalised care and support planning, personal budgets and to put people at the centre of their care to enable maximum choice and control about how needs are met.

#### **The NHS Five Year Forward View**

The NHS Five Year Forward view sets out how the health service needs to change, arguing for a more engaged relationship with patients, carers and citizens so that wellbeing can be promoted and ill-health can be prevented. Some aspects of what is needed to achieve this change can be brought about by the NHS itself. Other actions require new partnerships with local communities, Local Authorities and employers.

Some of the key relevant themes within the Five Year Forward View are as follows:

- The NHS will ensure that when people do need health services, patients will gain far greater control of their own care.

- The NHS will take decisive steps to break down the barriers in how care is provided between family doctors and hospitals, between physical and mental health, between health and social care.
- The NHS will also introduce integrated personal commissioning (IPC), a new voluntary approach to blending health and social care funding for individuals with complex needs.
- The NHS will find new ways to support carers, building on the new rights created by the Care Act.

Within the Forward View into Action: Planning 15/16, NHS England has identified a commitment to a major expansion of the offer and delivery of personal health budgets to people, where evidence indicates that they could benefit.

### **The Care Act 2014**

The Care Act 2014 came into force in April 2015 and superseded much of the legislation relating to health and social care and also legislation affecting unpaid carers.

The vision for the Care Act is for integrated care and support that is person centred, and shaped by the needs and preferences of those needing care and support. It requires local authorities to carry out their duties with the aim of joining up services, in line with the requirements on Clinical Commissioning Groups and NHS England as outlined in the NHS Act 2006, and in the context of Joint Strategic Needs Assessments and Health and Wellbeing Strategies.

In relation to the implications of the Care Act for the Collaborative Commissioning Groups, there are a number of considerations that must be made:

- Wellbeing must be at the centre of all the services and intervention that the NHS provides.
- The NHS will have to work in partnership to better understand unmet need to develop the approach to prevention that meets the true needs of the local population.
- Integration of information advice and information systems for the NHS and Local Authority partners.
- Development of systems for integrated assessment processes.
- Transitions arrangements to include integrated support planning around education, health and care.
- Take steps to integrate (and monitor/assure) direct payments from Local Authorities with other forms of public funding such as Personal /Health Budget (where all parties are in agreement).
- Facilitate partnership arrangements between CCGs and Local Authorities to ensure integrated provision of health and social care services.

- Cooperate when people with health and care needs move between areas.

### **The NHS Act 2006**

The NHS Act 2006 (including as amended by the Health and Social Care Act 2012) sets out a range of general duties on CCGs and NHS England which include requirements around involvement and engagement of users of health services at different stages of the commissioning process.

The CCG has a duty, for health services that it commissions, to make arrangements to ensure that users of these health services are involved at the different stages of the commissioning process including:

- In planning commissioning arrangements.
- In the development and consideration of proposals for changes to services.
- In decisions which would have an impact on the way in which services are delivered or the range of services available; and
- In decisions affecting the operation of commissioning arrangements where the implementation of the decisions would (if made) have such an impact.

## **4. Local Context**

### **Local Context:**

#### **Population**

The purpose of this section is to provide information about the historic and more recent information gathering that has been undertaken in relation to:

- The current group of people in receipt of health and social care respite provision.
- The potential (future) demand for respite, day opportunities and transport provision.
- Influencing legislation national agenda

Information has been collated to support the understanding about the needs for the services in the future and the scope and diversity of provision that may be required.

### **Sources of Information**

#### **Public Health England (PHE) Information**

Information extracted from the Learning Disability Health Profiles (2014-15) identifies that prevalence of learning disabilities in the population of the four Tees regions (Hartlepool, Stockton-on-Tees, Middlesbrough and Redcar and Cleveland) are higher than the national average in relation to the all age population of people with a learning disability but similar to other regions in the North East.

Stockton on Tees is the only region where the rate of all age prevalence is lower than the regional and national average. Information about prevalence per 1000 population in relation to Adults (18-64) in receipt of long term support from Local Authorities follows the same trend as the overall all age prevalence.

Information extracted from the Learning Disability Health Profiles (14-15) identifies that in terms of Quality and Outcomes Framework % rate prevalence the four Tees regions (Hartlepool, Stockton-on-Tees, Middlesbrough and Redcar and Cleveland) are **higher** than the national benchmark in relation to the all age population of people with a learning disability but similar to other regions in the North East. Stockton-on-Tees is the only region where the percentage rate of all age prevalence is lower than the regional and national average. Information about prevalence per 1000 population in relation to Adults (18-64) in receipt of long term support from Local Authorities follows the same trend as the overall all age percentage rate prevalence.

In relation to the future needs, it is important to consider the information maintained in respect of children and young people who have severe or profound and multiple learning disabilities. Public Health England information identifies that there are more children and young people per 1000 population with severe or profound and multiple learning disabilities in the Tees area than the regional and national average. This indicates that there will be proportionately more people in the future who will require support once they reach adulthood.

The vulnerability of the client group is highlighted by the national rate of safeguarding referrals per 1000 population. It is noteworthy however that the safeguarding referral rate in the North East generally is lower (or similar) to the national and regional average.

#### Office for National Statistics (ONS) Information

Further information about future population and potential demand has been obtained from Projecting Adult Needs and Service Information (PANSI) website which identifies a series of predictions.

The predictions from PANSI suggest that in every indicator set, there will be a reduction in the numbers of people who may require support than need support currently (in 2016) which contradicts the other sources of data.

The Office for National Statistics Census 2011 [Source: [www.nomisweb.co.uk](http://www.nomisweb.co.uk)] identifies that there are around 60,000 people in the Tees Valley regions that provide varying levels of unpaid care. This refers to people who provide care to any person who is in need of informal family support and includes people who care for disabled children and older people as well as any other person who requires unpaid care and support from family members or friends.

#### National Health Service England (NHSE) Information

NHSE Regional Clinical Network (North East and Cumbria) were not able to provide any specific data on learning disability that was relevant to the project.

NHSE have produced information that indicates that there are a higher number of NHSE and CCG commissioned placements in inpatient beds in the North East than anywhere else in England where the inpatient population.

The Transforming Care Board for Cumbria and North East England has an identified reduction trajectory of up to 70% for CCG and NHSE commissioned beds by 2020.

This will require a resilient, responsive and flexible community model of support to maintain the progress in line with the proposals. It is likely that there will be more people with complex needs, possibly with forensic backgrounds, who will return to be supported in community settings from secure services which may increase the demand for flexible and innovative respite provision that supports people to remain in the community. It is also important that the community services model reduces the rate of inappropriate admission back to inpatient treatment and assessment facilities.

#### Local Authorities:

There are 28 children and young people who are known to Local Authority transitions teams and special school nursing who are due to rise 18 in the next four years and who are likely to have significant complex needs and/or behaviour perceived as challenging and who will have respite needs.

There are a further 523 children and young people aged 14+ on Tees who are known to Local Authority children's teams who may have respite needs into the future.

#### Key Findings from Resources Accessed

Key findings about the local population of people with learning disabilities (and their carers) are identified below:

- The North East has a disproportionately higher number of people than anywhere else in England who have potential needs by virtue of their learning disability.  
[Public Health England]
- Over the next four years the numbers of people in the Tees area who are likely to be in receipt of services will remain fairly static although will be slightly fewer in total. (*Nb these are estimations and predictions only based on prevalence base rates and adjust these rates to take account of ethnicity and of mortality*).  
[Office for National Statistics – PANSI]
- There are more children and young people per 1000 population with severe or profound and multiple learning disabilities in the Tees Valley regions than the regional or national average. [Public Health England]
- There are 11 children and young people who will rise to 18 in the next four years who currently have learning disabilities and complex needs who currently receive overnight respite services at Baysdale, Roseberry Park Hospital.  
[Tees Esk and Wear Valleys NHS Foundation Trust]
- There are 16 children and young people who are rising to 18 in the next four years in the South Tees boundary and who will leave education and who will have learning disabilities and complex needs into adulthood and will be likely to need respite services.  
[Tees Esk and Wear Valleys NHS Foundation Trust – Special School Nursing]

- The reduction in numbers of people aged 18-64 with needs and in receipt of services could be due to the ageing learning disability population, as it is estimated that the number of people aged 70+ who have learning disabilities and will be in receipt of services will be approximately double. [Improving Health and Lives Disability Observatory]
- There is a significant number (in excess of 10% of the total population of the Tees Valley areas) of people who provide varying levels of unpaid care to people who need support by virtue of age, disability or ill health. [Office for National Statistics, Census 2011]
- The vulnerability of the client group is highlighted in relation to the national rate of safeguarding referrals per 1000 population, notably the number of referrals in the Tees Valley region is lower than the national average. [Public Health England]
- 72% of people in inpatient provision, on census day, were recorded to have behaviour that presented risk of violence to themselves or others. [Health and Social Care Information Centre – Learning Disability Census 2014]
- There are a higher number of NHSE and CCG commissioned placements in the North East than anywhere else in England. [NHS England]

## **5. Patient, Public and Stakeholder Involvement**

Initial engagement activity carried out between December 16 and February 2017 built upon historic engagement activity undertaken in 2015 and sought to obtain views from a wider cohort of people to ensure that the views, opinions and ideas about how respite services could be delivered in the future come from as broad a cross section of individuals as possible.

Engagement activity for the CCGs has been wide ranging and has included 206 individual points of contact:

Information collected supports understanding of respite and its impact for the people with learning disabilities who access respite services, and their families and carers. And also to determine how respite services can be improved in the future to continue to best meet the needs of people using them.

A range of engagement activities have been developed to seek views about the following:

- what respite means to different people (for example people with learning disabilities, families, carers and providers of services etc.),
- who benefits and how,
- what works well with current services,
- what needs to improve,

- how services could be delivered differently in the future to ensure that they fully meet the needs of those using them, in the most appropriate way,
- how people receive support in an emergency,
- how services work together (including transport).

Provisions were made to ensure that engagement activities were effective and accessible to people with learning disabilities, their families and carers. This has included working closely with local service user self-advocacy groups who have appropriate knowledge, skills and experience of working with people with learning disabilities, complex needs and families and parent carers. Information has been produced in easy read format and has been made available in a wide range of forums.

Clear information (including an easy read version) has been published on both CCG websites to provide details and the background to the review and also provides guidance about how to get involved, either by completion of a questionnaire or by becoming involved with the facilitated discussions. Background information about current respite service provision, and why the review is taking place has also been provided to support those taking part in the engagement activity.

A formal communications and engagement report has been produced to capture the findings of the initial engagement activities, a summary and easy read version of which have been made available publically and sent directly to those people who requested feedback.

Many efforts were made to invite individuals to participate within face to face engagement activities and/or for the completion of the parent carer survey. Methods used included:

- Appointment of a selection of local Voluntary Community Sector Organisations to undertake the engagement activities who are in touch with the local communities and are specialists in engaging with people with learning disabilities and their parent carers.
- Development of easy read information available on CCG websites since 21<sup>st</sup> December 2016.
- Three direct mail outs to the parent carers of individuals who currently access the bed based services (as identified by TEWV) on 3<sup>rd</sup> January 2017, 27<sup>th</sup> January 2017 and 14<sup>th</sup> February 2017.
- Direct mail out to the parent carers of those children and young people (aged 14+) who were accessing respite services at Baysdale, Roseberry Park on 3<sup>rd</sup> January 2016 and 27<sup>th</sup> January 2016.
- Events were planned at various locations and various times of the day including evening and weekends to increase the accessibility and availability of opportunity for people to get involved.

- Invitations and notification to specific events sent out to people who attend the Orchard Day Centre and their families and carers
- Attendance at various carer and service user forums, for example Learning Disability Partnership Boards, carers groups and parent carer forums and distribution of 200+ printed copies of the documentation at these events.
- NECS attendance at Local Authority Council meetings, e.g. Adult Services Committee, Hartlepool Borough Council.
- NECS attendance and briefing papers shared with Tees Valley Overview and Scrutiny Committee in October 2016 and in January and July 2017.
- Stakeholder briefing circulated across Local Authority services as of 21<sup>st</sup> December 2016 as well as through identified stakeholder groups.
- Promotion of engagement activities by Voluntary Community Sector Organisations through social media and other methods including information available on their website. In addition distributions were made to local libraries, ward councillors and the wider network of third sector organisations known to the Voluntary Community Sector Organisations.
- Posters and flyers available and accessible within the NHS commissioned bed based facilities and other services for people with learning disabilities, for example the Orchard Day Centre and Cumberland Resource Centre.
- Agreed communications statement about the engagement activities with TEWV

Most of the respondents to the questionnaire were in receipt of NHS commissioned services, with a small proportion of respondents who access respite services by means of direct payments/personal health budgets.

Key themes of the engagement activities and Carer questionnaire are as follows:

### **The engagement process**

- Concern from family carers primarily regarding the reasons behind the engagement exercise and a real fear that services would be cut.
- People using respite services noted that their wishes are not always listened to with regards to respite.
- There needs to be consideration of 'who' respite is for when thinking about future provision.
- Important to consider the impact of any changes to service delivery would have upon the benefits that are received by individuals.

### **What respite means**

- Respite means different things to different people, some people do not see day services as a form of respite, most people do not see services being offered at home as respite.
- Those who completed the questionnaire were parent carers for individuals who received services from a wide range of and sometimes multiple services (2, Bankfields Court, Aysgarth, Baysdale, The Orchard, Kilton View, Elmwood day

service, St Vincent's Day Service, Carers, PAs and Sitting service for hobbies and access to the community, TASC, Allensway, High Hills Day service, Ware Street. Catcotes Futures, Hartburn Lodge, Croft Centre, Emmsworth and Warren Road).

- Words and phrases such as “break”, “relax”, “peace of mind”, “safe place”, “rest”, “time out”, “recharge”, “anti-stress” were particularly common in relation to the responses from carers about what respite means to them.
- Parent carers of individuals have identified that respite for the person being cared for is about being in a ‘safe place’ where they can “socialise”, have a “change of scenery”, receive “emergency care”.
- Clarity about what respite is and a central point for information outlining all the respite options would be helpful to offer individuals and families greater clarity and choice.

### **The benefits of respite**

- There is a real appreciation for the services currently available and a fear of “total breakdown” without the services. Of those people who responded to the questionnaire close to 80% of people felt that the services available always or often meets their needs as carers and for the individuals who access the respite services.
- The opportunity for both parties to engage in different things, connect with other people and have a break from one another.
- Common words or phrases from parent carers who completed the questionnaire in relation to what respite brings them as carers included “holidays”, “family time” “housework”, “to just be me for a while” “work” “socialise and go out with friends”.
- Knowing that the health needs of their relative would be met and being able to trust staff. Words and phrases that were common within the questionnaire responses were things like “well trained staff”, “staff who have known my son for a long time”, and “dedicated professionals” and the “most caring people you could meet”.
- Common words or phrases used to describe what respite does to help the person that accesses the service included “making friends” learning new skills”, “activities or trips” “free time” “chill time” “medical activities/appointments”, “company of peers”.
- Access to new opportunities and developing greater independence important for those using respite services.
- Peer support for families and the opportunity to make friends for those who access respite services.

### **Resources**

- General awareness of how respite is funded would be helpful.
- Use of direct payments / personal health budgets would appear to be more prevalent amongst younger individuals and their families and in certain areas, for example Hartlepool.
- There can be debates around responsibility for provision of respite that are difficult for families.
- Clarity around the funding process would reduce what is perceived to be an added pressure on families.
- Staffing for people who use direct payments/personal health budgets can be problematic and can make consistency of care difficult.
- Location of respite is not a concern.
- A small number of family carers thought 2, Bankfields Court was no longer fit for purpose.

- Anxiety about whether wider community resources are equipped to meet the complex needs of people who require respite services.
- A mapping exercise to identify what is currently available and where the gaps are may help.

### **Improvements for the future**

- Nearly 60% of the people who responded to the questionnaire felt that there could be improvements to make respite services better meet their needs as carers. Common suggestions for improvements included “improving care”, “more respite time”, “more flexible services”, “improve facilities”, “more staffing resources”.
- Nearly 40% of the people who responded to the questionnaire felt that there could be improvements to make services better meet the needs of the person that they care for. Common suggestions for improvements were “better care” “better facilities”, “more flexibility” “improve transport arrangements” “more respite time”.
- Planning respite needs to be able to be booked in advance as well as at shorter notice and be flexible around the needs of the individuals not the services.
- Choice, particularly for those people with complex needs.
- Emergency provision should not impact on already planned respite
- Coordination, particularly for those Young People in Transition in relation to sources of funding, equipment and other resources.
- Information, a shared understanding of what respite means and all the possible options around this.

## **6. Market analysis and procurement options**

Engaging with the market can assist commissioners in gaining a stronger understanding of the level of interest, capability and capacity within the market for the provision of the required services. Alongside this, market engagement can (if required) be utilised to gain feedback from potential providers in both the development of a service specification and defining an indicative financial envelope / pricing mechanisms for the required service(s).

A Prior Information Notice (PIN) was issued to the market on Contracts Finder and the Official Journal European Union (OJEU) on the 26 January 2017 to alert the market of the CCG intention to engage with potential providers through a Request for Information (RFI), in relation to respite services for adults with learning disabilities and/or complex needs. The RFI documentation was available to all organisations who expressed an interest in the PIN via the NECS E-Procurement System (Proactis). The purpose of the RFI exercise was to gain feedback on:

- The marketplace;
- The service model and service activities;
- Contractual model; and
- Understand the definitions providers used to define respite services.

The RFI exercise concluded on the 16 February 2017 and resulted in 16 expressions of interest and 4 potential service providers who responded to the RFI.

The market engagement highlighted that there is sufficient interest in the service provision from the market to ensure competition if the service was to be procured. There are opportunities for the CCG to work with providers to ensure better services to ensure better outcomes for patients and opportunities for providers to develop a more patient-centred service that would allow patients to be involved in decisions about their care.

The market engagement also identified weaknesses in that there is ambiguity in the process within the Local Authority and CCG to allocate resources such as personal health budgets. It also identified poor payment response from Local Authorities and/or CCGs to small providers thus hindering their financial viability and resource allocation. The increase in costs, and or lack of funding threatens providers to maintain appropriate staff to deliver a bespoke service.

Recruitment of trained staff is also a big issue among providers and maintaining that level of staffing contributes to not being able to react or be flexible in crisis and or emergency situations.

Further market engagement is proposed to explore these models in more detail. Providers will be invited to a face to face workshop session where they can share details of their experience and their service delivery models as part of the development work.

### National Market/Service Models

Prior to undertaking the RFI process, information has been obtained over time from a variety of sources to look at models in place across the country and to consider and evaluate the varied options and models that exist.

Further investigative discussions focussed on the following areas (in addition to following up any findings that were made from the resources available online):

- 1) Currently commissioned health/social care arrangements for adults (and young people in transition) with a learning disability for respite provision - service model in place.
- 2) Alternative respite options for to access with personal budgets (Direct Payments/PHBs/ISFs).
- 3) Eligibility criteria for respite provision for social care provision. Determination of whether the person's needs are social care needs or health care needs.
- 4) Options (and funding sources) available for people with more complex needs (including those people whose behaviour challenges services).
- 5) The successes and benefits of developing options.
- 6) The downfalls of developing options.
- 7) Action taken to remedy or mitigate risks.
- 7) Consultation undertaken, process, findings and feedback.
- 8) Learning from the experience/reflection.

Information and learning has been taken from Moray, Dundee, Tameside, Southampton, East Sussex and Shropshire.

From the discussions undertaken it is possible to draw the following conclusions:

- All areas have endeavoured to develop the arrangements for respite care for adults with learning disability.
- All models consist of a buildings based aspect together with a range (diversity and scope varies) of other options, either via commissioned services or those accessed by direct payments.
- There is a common desire to do more and create a wider base of activities and enable people to receive a choice and the opportunity to perhaps pick and mix how they receive their support.
- There is a need to develop the services that are available currently and widen the availability of new and personalised options for people.
- Re-design will enable the delivery of the aims of Transforming Care agenda and support the Local Authority and CCG obligations to carers under the Care Act.
- It is crucial that services, agencies and authorities work together to ensure that people receive excellent community based support that meets their individual needs and personal preferences to promote personal wellbeing and the ability to remain at home in their own environments within community settings.
- It is work in progress in most geographic areas and the challenges faced by Local Authorities and CCGs are in common.
- Consultations have been undertaken in each area in relation to proposals and changes and in nearly all examples, within the current cohorts accessing buildings based settings there has been a reluctance to change and evident anxieties about closure of long standing and long serving provision.
- More often than not, children and young people coming through transitions are more engaged in change and in a large proportion of cases have already gone through resource allocation procedures as part of their access to Children and Young People services and that the opportunity to take direct payments and utilise innovative personalised services is more of an expectation.
- Consultation processes have shown the value people hold in services to support carers and the people who they care for and the importance of getting their involvement right and at the right time to enable them to be influential in the planning of services.
- It is important to ensure that the plans for re-provision and remodelled services are coherent and consistent and that alternative options are made available before existing services diminish.

## **7. Financial Summary**

It is not anticipated that the agreed finances for respite services will reduce. In terms of services available in the future these are therefore unlikely to cost less but will achieve better and more varied outcomes for the people who receive them. In the future, services will be needs led rather than demand led.

Costs for new flexible outreach community service(s) are in the process of development.

**For further information please contact the Communications and Engagement Team on 0191 374 2795 or by email at [NECSU.engagement @nhs.net](mailto:NECSU.engagement@nhs.net)**