

## Stakeholder briefing

# Tees respite services independent consultation report published

In September 2017, NHS South Tees Clinical Commissioning Group (CCG) and NHS Hartlepool and Stockton-on-Tees CCG (the CCGs) launched a 10-week formal public consultation on proposed changes to respite services for people with a learning disability, complex needs and/or autism.

Health based respite is currently provided to just under 100 people from the Tees area, and their families/carers, who currently access the service from Bankfields Court in Middlesbrough and Aysgarth in Stockton-on-Tees.

During the consultation, which closed on Friday 10 November, the CCGs engaged with people who currently access the services as well as their families, loved ones and carers.

Four, wider public meetings were held in Middlesbrough, Redcar, Hartlepool and Stockton that were attended by a total of 78 people.

A specialist voluntary sector partner was commissioned to run 21, independently facilitated engagement sessions attended by 90 people, which included 51 people with learning disabilities and 37 family members/carers.

The CCGs also engaged with over 400 stakeholders, including the Tees Valley Overview and Scrutiny Committee, local MPs and councillors, Healthwatch and many others.

As the consultation progressed, key questions or issues were captured and responded to in a Frequently Asked Questions document which is attached.

In total, 141 completed surveys were received in response to the consultation. All of the feedback collated as part of the consultation has now been independently analysed and today (Monday 11 December 2017) the independent report of the consultation will be made available on the CCGs websites.

The CCGs are keen that people have the opportunity to comment on the report, to ensure it reflects the feedback they provided as part of the consultation. There are a number of ways people can respond and these are detailed below:

**Telephone:** 0191 374 2795

**Email:** [necsu.engagement@nhs.net](mailto:necsu.engagement@nhs.net)

**Write to:** Communications & Engagement Team, North of England Commissioning Support, John Snow House, Durham, DH1 3YG

**Facebook:** For those living in the Middlesbrough and Redcar and Cleveland area, search for 'NHS South Tees Clinical Commissioning Group'. Search for 'NHS Hartlepool and Stockton Clinical Commissioning Group' if you live in the Hartlepool or Stockton areas.

**Twitter:** @SouthTeesCCG or @HaSTCCG

You can download the independent consultation report on the CCG websites – [www.southteescCG.nhs.uk](http://www.southteescCG.nhs.uk) or [www.hartlepoolandstocktonccg.nhs.uk](http://www.hartlepoolandstocktonccg.nhs.uk). Paper copies are available on request by calling 0191 374 2795. Please ensure your feedback is returned by **Thursday 11 January 2018**.

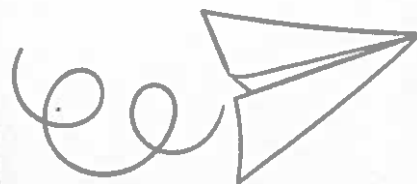
The report will also be shared with key stakeholders, such as the Tees Valley Joint Health Overview and Scrutiny Committee, local MPs, Healthwatch and local authorities.

The independent report, as well as feedback received about it will be used to help the CCGs make a decision on the future of respite services across Tees. A decision is expected to be made at a meeting of the CCGs' Governing Bodies at the end of January 2018. Members of the public are welcome to attend this meeting and details will be published on the CCGs' websites once confirmed.

Background information on the consultation is available at:

[www.hartlepoolandstocktonccg.nhs.uk](http://www.hartlepoolandstocktonccg.nhs.uk)

[www.southteescCG.nhs.uk](http://www.southteescCG.nhs.uk)

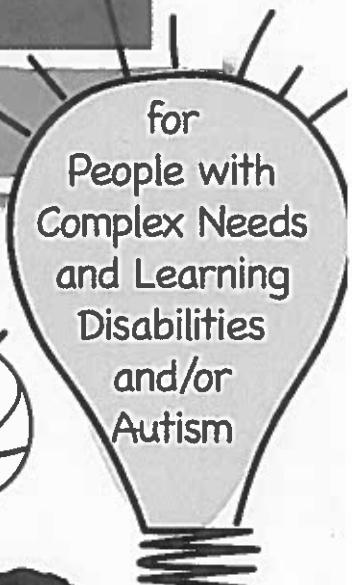


Respite



# Opportunities

## and Short Breaks



for  
People with  
Complex Needs  
and Learning  
Disabilities  
and/or  
Autism

NHS Hartlepool and Stockton-on-Tees  
Clinical Commissioning Group  
and  
NHS South Tees Clinical Commissioning Group  
Prepared by Consultant Researcher and Data Analyst, Jenny Harvey  
December 2017



Independent Reporter – Jenny Harvey

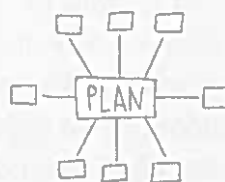
This report has been developed by an independent report writer to provide an independent analysis of consultation feedback, in line with best practice consultation.



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# 1 Executive Summary



## Background

Respite Opportunities and Short Breaks for People with Complex Needs and Learning Disabilities and/or Autism was a public consultation about the future of respite services in Teesside. The consultation was run by NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group and NHS South Tees Clinical Commissioning Group over a 10 week period, from 4th September 2017 to 10th November 2017.

The CCGs are looking to improve the way in which respite for people with learning disabilities and complex needs and/or Autism is delivered for Hartlepool, Stockton-on-Tees, Middlesbrough and Redcar and Cleveland. It is recognised that current NHS respite services are not sustainable, equitable or flexible enough to meet the current and changing needs of the local population.

Both the national Transforming Care Programme and the NHS Five Year Forward View include 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. Furthermore, the Care Act 2014 strengthens Local Authority and CCGs shared obligations to carers to ensure that they are supported in their roles.

A needs and responsibilities document was produced by the CCGs which was then followed by a period of informal engagement which ran from December 2016 to end of February 2017 to help to understand respite and its impact for people with learning disabilities and complex needs and/or Autism who access respite services, and their families and carers across the Teesside area. Feedback from the informal engagement, a desk top review as well as market research with potential new and existing providers led to the development of specific proposals on how respite services could be delivered. The proposals also took into account direction from recent national policies.

These proposals formed the basis of the Respite Opportunities and Short Breaks public consultation in which service users, family and carers, staff and stakeholders and the wider public were given the opportunity to have their say.

## Consultation options

The two options put forward for consultation are the options that were felt to best meet the needs and identified priorities for service users, their families and for the CCGs. Several scenarios were developed for how CCGs might be able to make available respite, short break and day opportunities based on what people said during the review carried out between December 2016 and February 2017. The seven scenarios were taken forward and then evaluated using an appraisal criteria (page 10 of the Consultation Narrative document, Appendix - 12.3). From this Options 1 and 2 were considered as viable options and these were taken to consultation.

With both options, there will be a new needs led assessment and allocations process which will change how resources are allocated and with both options there will be the opportunity to have different types of respite / short breaks. Both options will be delivered within the existing £1.5 million budget. The differences are:

**Option 1** – people would not get bed based respite from 2 Bankfields Court and Aysgarth, but could get alternative bed based respite services elsewhere e.g. in another residential community setting or a hotel, with the appropriate support. Depending on the assessed needs and resource allocation, people will be able to access alternative community based activities with appropriate support, in addition to, or instead of, bed based provision. Different community bed based respite services are often less expensive than hospital bed based provision and service users' allocated resources may be able to go further.

**Option 2** – some people could still go to 2 Bankfields Court and/or Aysgarth for bed based respite services, if this is how they chose to receive their respite. Depending on their assessed need and resource allocation they may have the opportunity to access alternative community based services in addition to or instead of bed based services. Because of the need for ongoing investment with the current NHS services there may be fewer opportunities for people to access alternative respite and short break opportunities.

## Consultation process

Changes to learning disability respite services primarily affects approximately 90 people currently using the service. A comprehensive programme of communications and Public Relations activity was planned to engage as wide an audience as possible, to raise awareness of local services and allow anyone the opportunity to participate in the consultation. In addition, consultation materials were distributed to a wide range of appropriate settings in each of the Local Authority areas (e.g. libraries, GP Practices, dentists, day services, carers meetings, partnership boards, job and leisure centres) as well as briefings to 386 key stakeholders, with a request to share information across their networks.

Recognising the complexities of service users, every effort was made to ensure that information was presented in a clear, easy to understand format with the use of easy read materials to complement more detailed documents. In addition, individuals with learning disabilities were offered to support to participate in the consultation.

As per the pre-engagement work, community and voluntary sector organisations with extensive experience and skilled at working with people with learning disabilities, and their families, were identified to be best placed to facilitate elements of the engagement.

The following summarises the engagement methods used in the consultation. In total, 385 points of contact were made. 15% of the overall sample were people with learning disabilities, 46% family / carers, 15% members of staff of existing health respite services and 18% other individuals / stakeholders (the respondent type of the remaining 6% was unknown).



Engagement method	Number of individuals
4 public events held by CCGs supported by North of England Commissioning Support Unit (NECS) representatives (one in each Local Authority area)	89
21 facilitated discussion groups run by voluntary and community sector organisations (a minimum of three were held in each Local Authority area)	90
Staff drop-in sessions at current health respite services	45
An engagement event for VCS organisations held by Inclusion North (an organisation with extensive experience of working with people with learning disabilities, their families and carers)	2
Online and paper questionnaire for people with learning disabilities, family members, carers, stakeholders and members of the public	141
Individual / organisation submissions	18
<b>TOTAL</b>	<b>385</b>



All feedback gathered was analysed by an independent consultant data analyst. The independent report produced contains information about the planning and development of the consultation, the communications and engagement activity, the analysis of the feedback and the summary of the consultation findings.

## Consultation findings

A number of those engaged, expressed concern with the consultation proposals as they perceived them to be ambiguous and lack detail as to exactly what will be provided and where. For this reason, some felt it was difficult to make an informed choice, whilst others felt that it should be up to service users to decide. Furthermore, although some recognised that changes to respite provision needed to be made, the lack of specific detail in Option 1, made it difficult for people to choose this option, or even consider it as an option. The CCGs responded to this in the FAQs. Community bed based services under Option 1, could be services provided from care homes, shared lives placements or other community setting for example adapted premises or properties where staff will be available and have the right skills to support people safely.

The actual locations from which bed based provision for people with Learning Disabilities and Complex Needs will be determined following a procurement exercise under Option 1. At this time there have been no providers identified as this will be part of the wider procurement, which can only be commenced following completion of the consultation exercise.

For those that were able to provide an opinion, a resoundingly greater preference for Option 2 was observed – continuing to buy bed based respite at 2 Bankfields Court and Aysgarth.



Findings from the questionnaire support this, with 90% of respondents fully or partially supporting Option 2 (74% & 16%, respectively), compared to 26% that fully or partially supported Option 1 (15% & 11%, respectively). Although numbers are low and caution must be applied, the lowest level of support for Option 2 was observed among those who completed the questionnaire in Hartlepool where local NHS bed based respite is currently unavailable (total 55%; 33% supporting the option and 22% partially supporting the option 2).

There were however, a small number of respondents that talked positively about, and favoured Option 1 – buying a range of bed based services to replace existing bed based respite services. Among others, these tended to be parents / carers whose loved ones do not fit the criteria for current bed based respite, as well as individuals from Hartlepool who felt that this option had the potential to provide local bed based respite. Again, findings from the questionnaire support this with the greatest proportion of those from Hartlepool fully or partially supporting Option 1 (44% & 22%, respectively). The greatest dissatisfaction for Option 1 can be seen among those who lived in Redcar & Cleveland and Stockton-on-Tees with 71% and 75% not supporting the proposal respectively.

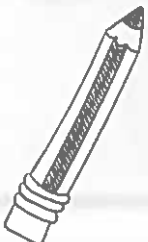
The following summarises the key comments put forth in favour of each option. It must be noted the arguments for Option 2 were much more strongly supported.

## Option 1

- Provides a possible solution for some of the issues faced in accessing bed based provisions
- Potentially provide individuals in Hartlepool with local bed based respite
- Provides greater choice and more opportunities for people with learning disabilities and complex needs to have their needs met, as well as having a positive impact on their family and carers too

## Option 1

- Current bed based respite services provide excellent care, which will be difficult to replicate within the community
- Community based respite is not appropriate for those with very complex health needs
- Concern around reducing overnight provision / great demand for bed based respite
- Negative impact of change on service users and family carers
- Alternative community providers will not be able to deliver the same level of quality as current bed based respite services



## Next steps

Feedback from the consultation will now be used by NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group and NHS South Tees Clinical Commissioning Group to inform the decision about how respite services for people with learning disabilities and complex needs and/or Autism are delivered across the Teesside area.

A final decision about what respite services will look like in the future will be made week commencing 29th January 2018. Information about the final decisions will be published on the CCGs websites and will be shared with staff, all individuals and their families and carers and other key stakeholders.



## 10 Summary of findings



The following summarises the key findings from all of the engagement methods used in the consultation.

Among consultation respondents there was a high level of dissatisfaction with the consultation proposals as they were perceived to be ambiguous and lack detail of exactly what will be provided and where. For this reason, some felt it was difficult to make an informed choice, whilst others felt that it should be up to service users to decide. This was addressed at the public events and within the live FAQ document, which stated, *'The CCGs are unable to identify providers until completion of the procurement exercise and this can only commence, once the consultation is concluded'*.

Although some recognised that changes to respite provision need to be made, again the lack of specific detail in Option 1 (i.e. bed numbers and locations), made it difficult for people to choose this option, or even consider it as an option.

For those that felt able to provide an opinion, a resoundingly greater preference for Option 2 was observed – continuing to buy bed based respite at 2 Bankfields Court and Aysgarth. Findings from the questionnaire support this, with 90% of respondents fully or partially supporting Option 2 (74% & 16%, respectively), compared to just 26% that fully or partially supported Option 1 (15% & 11%, respectively).

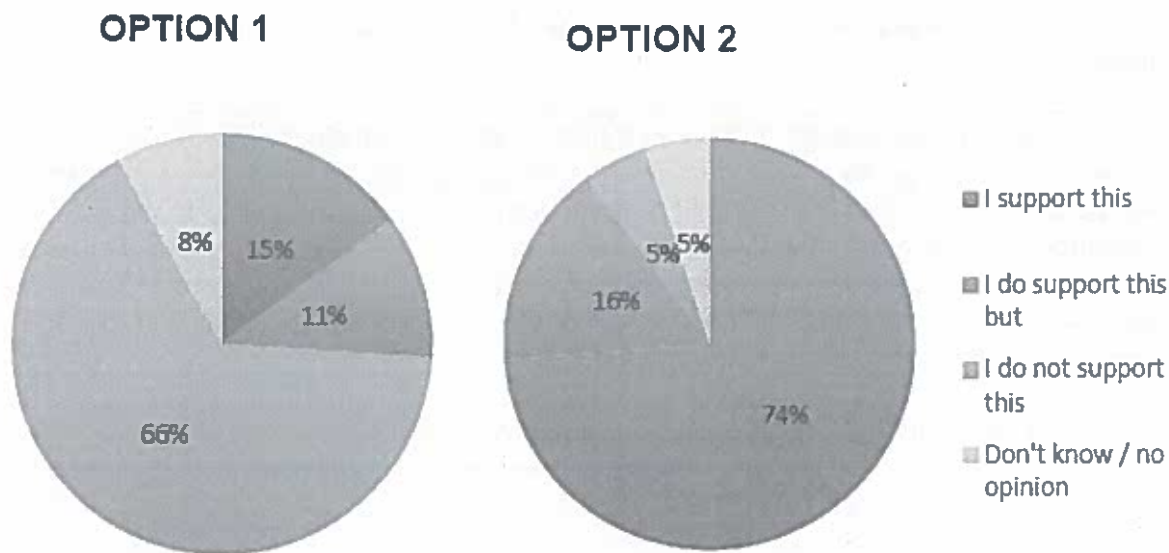
In terms of the support for Option 2 by Local Authority area, similar proportions of questionnaire respondents fully or partially supported the proposal in Redcar & Cleveland (total 96%; 75% fully and 21% partially supporting the proposal), Middlesbrough (total 93%; 80% fully and 13% partially supporting the proposal) and Stockton-on-Tees (total 96%; 71% fully and 25% partially supporting the option). The lowest level of support for the option was observed among those who completed the questionnaire in Hartlepool where local bed based respite is currently unavailable (total 55%; 33% supporting the option and 22% partially supporting the option). However, caution must be applied as Hartlepool had the smallest number of participants responding to the questionnaire.

Overwhelming concern was expressed in relation to bed based respite services being changed, reduced or taken away. Individuals emphasised the need for these services to remain by discussing the possible consequence of these changes on the people directly affected.

There were however, a small number that talked positively about, and favoured Option 1 – buying a range of bed based services to replace existing bed based respite services, as stated previously 15% of questionnaire respondents supported and 11% partially supported Option 1 (66% did not support this option, and the remaining 8% were unsure or did not have an opinion). Among others, these tended to be parents / carers whose loved ones do not fit the criteria for current NHS or Local Authority bed based based respite, as well as individuals from Hartlepool who felt that this option had the potential to provide local bed based respite.

Again, findings from the questionnaire support this with the greatest proportion of those from Hartlepool fully or partially supporting Option 1 (44% & 22%, respectively). However, again caution must be applied to these findings due to response rates. The greatest dissatisfaction for Option 1 can be seen among those who lived in Redcar & Cleveland and Stockton-on-Tees with 71% and 75% not supporting the proposal respectively.

**Figure 15: Questionnaire respondents' preference for the consultation proposals**



### Option 1

The following summarises the views of individuals who favoured this option. Firstly, the proposal was considered to provide a possible solution for some of the issues faced by family carers in accessing bed based provisions; for example respite being cancelled due to emergency admissions and limited flexibility in requesting specific dates / changing planned respite.

Furthermore, stakeholders who attended the public event in Hartlepool discussed, as well as two family carers and one member of staff, discussed how the option could potentially provide individuals in the area with local bed based respite. However, concern was expressed about the current lack of appropriate respite that could be used in Hartlepool.

A small number of family carers and stakeholders who attended the consultation events recognised that the option would provide greater choice and more opportunities for people with Learning Disabilities and complex needs to have their needs met, as well as having a positive impact on their family and carers too. This was particularly felt to be the case for those that don't meet the criteria for current health bed based respite services or for social care services.

Choice was considered a positive step by some adults with Learning Disabilities who attended the facilitated discussion groups. They particularly welcomed the opportunity to take a holiday and for people to feel part of the wider community. However, they had a few concerns regarding safety, as to whether alternative settings could cater for people's needs. This was identified to be a potential barrier for some families / carers.

## Option 2

The views put forth for retaining current bed based respite services in the different engagement methodologies are summarised below.

### **Current bed based respite services provide excellent care**

There was a widespread acknowledgement by family carers and stakeholders of the high-quality, reliable and consistent care that is provided at the current bed based respite services, with individuals feeling passionately that these services need to continue. This was also recognised by members of staff from the respite services themselves, who stated how staff pride themselves on the quality of care that they provide to service users and their families. Specific comments made in relation to the standard of care, related to:

- The vast knowledge and expertise of staff
- The relationships and trust that exist between service users, staff and carers - enabling carers to relax and enjoy their period of respite
- High staff retention, leading to consistency of care
- The ability of the provisions to cater for individuals with very complex health and social needs
- Provision of emergency respite (although it was noted that data does not support this)
- The range of activities that bed based staff offer and support service users to take part in.

These discussions repeatedly led to questions as to why change is required, as well as concerns of how this standard of care would be replicated within the community.

### **Community based respite is not appropriate for all**

Although it was recognised that some would benefit from accessing alternative respite options, there was great concern that the complex needs of some service users would not be able to be met through community based respite services. Some felt that these individuals would therefore be unable to access respite services going forward. Issues related to staff training, the appropriateness of venues (i.e. B&Bs, hotels, care homes), safety, individuals not being able to cope / not wanting to access activities in the community and the lack of consistency of care.

It was felt strongly by some family carers that hospital bed based respite needs to remain to cater for these individuals. Family carers who responded individually to the consultation felt that changing respite opportunities for very vulnerable individuals to provide choice for others on the same budget was unfair.

## **Reducing overnight bed based provision**

For most, overnight bed based care was considered the most important element of respite care, with the highest number of questionnaire respondents (73%) selecting this option from a list of possible flexible community based respite services. Without this provision, many felt that it wouldn't be respite, as day activities do not always provide adequate breaks for carers. It was strongly felt that in the public events that CCGs should focus on getting bed based respite right before looking at community based activities.

In acknowledgment of the current demand for beds, family carers, staff and stakeholders raised concerns about losing / reducing provisions at 2 Bankfields Court and Aysgarth, particularly with demand on respite services forecasted to increase. It was felt that the focus needs to be on continuing to provide and develop existing bed based services, as this is what is needed and where individuals are happy.

Queries were raised as to how emergency provision would be affected, as access to emergency respite is vital.

## **Impact of change on services users and family carers**

Routine and structure are extremely important for individuals with Learning Disabilities and Autism. Changing the way in which Learning Disability respite provision is delivered was therefore anticipated to result in major problems for service users including extreme changes in personality, temperament and sleeping patterns, which could potentially lead to more crisis situations, costing the NHS more in the longer term. This was identified by members of staff and family carers.

Bed based respite is considered an essential provision for family carers to enable them to have a well-earned break, a night of undisturbed sleep, a chance to lead a 'normal' life and to spend quality time with their other children, partners and friends. For many parents / carers, respite is knowing and trusting that their loved one is safe and being cared for, rather than the range of different opportunities that are available. By offering services in the community, members of staff felt that family members would always feel 'on call' and therefore unable to 'switch off'.

There were strong concerns among some family carers that they might potentially lose respite services if their loved one is unable to be supported within the community or is unable to cope with change. If this were to happen, some parents / carers questioned their ability to cope, with concern that their loved one might have to go into residential care.

Issues were also raised by family carers with regard to individuals receiving support in inappropriate environments. This was felt to create long-term problems for carers when they return home.

## **Alternative community providers will not be able to deliver the same level of quality as current bed based respite services**

The general feeling among family carers, staff and stakeholders was that alternative providers will not provide the same quality of care that is delivered in current bed based services. It was perceived that staff employed by other providers have a lower rate of pay than NHS staff resulting in lower motivation and higher staff turnover, leading to a lack of consistency of care for service users. In addition, there were concerns that staff will not have the sufficient

training and expertise to be able to care for individuals with extremely complex needs (including severe / life-threatening epilepsy and high-functioning Autism). Some family carers discussed past experiences of alternative providers not being able to adequately care for service users, and/or their loved one being turned away as they were unable to meet the needs of the individual.

Questions were raised by family carers in the facilitated discussion groups about contingency plans due to the lack of continuity of private sector providers, and whether the NHS would then incur more costs in having to pick up the slack.

Other views put forth in favour of Option 2 but to a lesser extent included concerns over losing the community aspect of bed based provisions resulting in more isolation for individuals, as well as concerns about the cost implications of Option 1 - providing bed based respite in different locations and settings.

### **Flexible community based respite services**

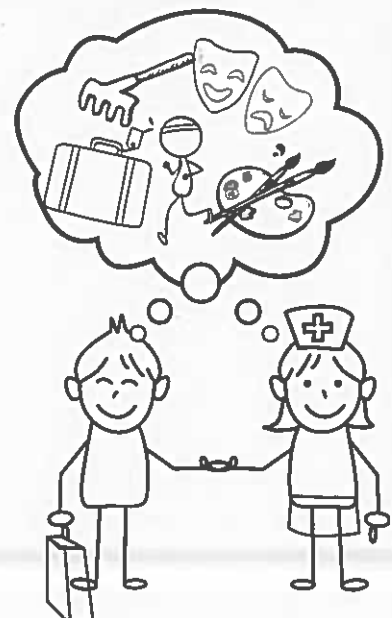
When asked to select preferred options from a menu of community based options, 46% of questionnaire respondents selected 1:1 help or support to use respite in the community, 39% flexible community based leisure and activity options and 32% holiday short / break options.

The least preferred option was support at home, with 27% of questionnaire respondents selecting this as an option. There was a widespread consensus that this is not considered respite as it did not give carers a break from their loved one, as well as being perceived as intrusive. Additionally, it was felt important by some of those that attended the public events that individuals are supported outside of the home to promote independence.

It is apparent from these questionnaire findings and from the open discussions that whilst one option of community based respite might suit one service user and their parent(s) / carer(s), this would not be appropriate for another. This highlights the importance of developing a range of age-appropriate options to suit service users with a diverse set of needs, interests and preferences. There was however, an underlying concern among family carers, staff and stakeholders that the suggested options could exclude those with greater health and social needs.

Although providing choice, was considered positively by some people with Learning Disabilities and family carers, there were concerns raised by other family carers that this would have negative implications for service users who want / need familiarity and structure.

Additional points about the delivery of community based respite services, raised for consideration by the CCGs included:



- Access to provisions close to home provide peace of mind for carers
- Cost implications for provision of community based services i.e. increased staffing ratios for supporting very challenging adults in the community, costs of activities, transport costs, medical support and equipment
- Providers must be flexible to provide vital support for emergencies (familiarity is preferred in these instances)
- Burden on parents / carers to continually organise activities
- Importance of protecting friendships within respite care; allowing friendship groups to access services together to prevent people becoming isolated (identified by family carers and individuals with Learning Disabilities)
- Importance of transitional planning; ensuring that parents / carers have the opportunity to look closely as to what is needed and are supported in the process. It was suggested by a few that this needs to be longer than what is proposed
- Involvement of family carers and staff in the procurement process
- Expense of accessing community respite services; transport needs to be considered and provided, where necessary

### **Assessment and allocations process**

There was recognition among some family carers and stakeholders that the assessment and allocations process needs to be improved, with some family carers perceiving that they should be part of this process.

It was emphasised that the process must take into account contributions from multiple sources including parents / carers, as well as consider access and transport. In addition, it was felt changes need to be made in partnership with the Local Authorities, along with an agreed way to joint work in the future to assess and determine need. As with all queries raised in the consultation, this was addressed in the FAQ document.