Transforming Care: Review of Respite Services for People with Learning Disabilities and Complex Needs

Communications and Engagement Report

March 2017
This document can be made available in different languages and formats on request.

Please contact the Communications and Engagement Team on 0191 374 2795.

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1. Executive Summary

A period of informal engagement commenced in December 2016 and continued across January and February 2017. This will help NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group and NHS South Tees Clinical Commissioning Group (‘the CCGs’) to understand respite and its impact for people with learning disabilities who access respite services, and their families and Carers.

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

Engagement activity included:

- a work placement for two people with lived experience to support with the facilitation of engagement and to support the involvement of other people with learning disabilities
- surveys for families and carers
- discussion groups across the CCG areas led and facilitated on our behalf by independent voluntary sector organisations with expertise in supporting people with learning disabilities, their families and carers
- collection of information about people’s experiences of respite
- distribution of information and engagement materials to relevant stakeholders including stakeholder briefings sent to relevant stakeholders
- CCG and NECS attendance and discussion at Learning Disability Partnership Boards and other relevant public meetings including Tees Valley Joint Overview and Scrutiny Committee
Provisions were made to ensure that engagement activities were effective and accessible to people with learning disabilities, their families and carers. This 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 was produced in easy read format and was made available in a wide range of forums.

NECS, on behalf of the CCGs have worked with Inclusion North to co-ordinate and quality assure a series of sessions to be facilitated by relevant voluntary and community sector organisations to ensure that the CCGs can actively listen to the views of the people who participate.

The engagement activities concluded on 24th February. The numbers of individuals/groups engaged were as follows:

Family carers: 55
People with learning disabilities: 50
Family carers and people with a learning disability: 9
Representatives of voluntary and community sector organisations: 6

In addition to these formal facilitated face to face discussions, 86 people completed questionnaires for families and carers of people who use respite services and those who have used it in the past or who may use it in the future.

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 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 (Bankfields, Aysgarth, Baysdale, The Orchard, Kiltonview, Elmwood day service, St Vincents 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 Raod)
- 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 of phases 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 Bankfields was perhaps 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.
2. Background

The Communications and Engagement Team of NHS North of England Commissioning Support (NECS) supported NHS South Tees Clinical Commissioning Group and NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group (‘the CCGs’) to actively engage members of the South Tees and Hartlepool and Stockton-on-Tees populations.

The aim of the engagement was to inform a review of respite services for adults with learning disabilities (including complex needs) in the two CCG areas. This was to ensure that these services will appropriately meet the needs of the population now and into the future in the context of the wider Transforming Care agenda.

Both Transforming Care 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 their own needs are met.

Hartlepool and Stockton-on-Tees CCG and South Tees CCG recognise the need to co-design and implement an effective, resilient and flexible community model of services to support and facilitate timely discharge from inpatient setting. Another key focus for Transforming Care is to ensure that people with Learning Disabilities, including those who have challenging needs, can live full and good lives within their local communities and receive the support they need to enable them to do this.

The Care Act 2014 strengthens Local Authority and CCG obligations to Carers to ensure that they are supported, valued and recognised within their roles and also to ensure that they are influential in the development of appropriate services to meet both their needs and the needs of the people who they care for.

The review focused on health respite services for people with complex needs. The CCGs are working in partnership with the four Local Authorities across the South
A period of informal engagement was conducted to help the CCGs understand:

- What the expression ‘respite services’ means to people with learning disabilities, their families and carers
- What people with learning disabilities, their families and carers think works well with current respite services for people with learning disabilities
- How people with learning disabilities, their families and carers think respite services for people with learning disabilities could be improved.

This engagement will help to inform the development of a number of possible ‘scenarios’ for the provision of respite services for people with learning disabilities in the future. These scenarios will be ideas on how learning disability respite services could be further developed or delivered differently to best meet the needs of the local population.

It is important to note that there will be no fundamental change to the type of respite services currently available for people with Learning Disabilities while this review is conducted. Following the review, scenarios that are developed that are viable and sustainable in the longer term may be taken forward as proposals for change to improve respite services for people with learning disabilities.

Any proposals for significant change will be subject to formal consultation with the public. If any proposals for change are not significant, these will be subject to a further period of informal engagement, as opposed to formal public consultation.

The CCGs are working with a joint Overview and Scrutiny Committee, with members from all four Local Authorities, throughout the review. The Overview and Scrutiny Committee will be kept informed on progress and feedback.
Following the initial period of informal engagement, the Overview and Scrutiny Committee will also give its view on whether or not any proposals for change should be subject to formal public consultation.

The CCGs will also make sure that Health and Wellbeing Boards, HealthWatch organisations, MPs and Local Councillors are kept informed of progress of the review and any proposals for change that may be developed.

### 3. Communications and Engagement Objectives

Engagement activity aimed to realise the following SMART (Specific, Measurable, Achievable, Relevant, Time framed) objectives:

- To develop, deliver and maintain clear and concise messages to the public and stakeholders across the engagement activity period from w/c 28 November 2016 to w/c 06 February 2017
- To develop effective engagement mechanisms and activity that are accessible to people with learning disabilities, their families and carers by w/c 28 November 2016 (the start of the engagement activity period)
- To actively listen to and understand the experience of people with learning disabilities, their families and carers across the engagement activity period from w/c 28 November 2016 to w/c 06 February 2017
- To collate and analyse feedback from those taking part in the engagement activity, in order to understand relevant themes, priorities, challenges and issues identified by w/c 13 February 2017
- To use the feedback to write an engagement report to report back findings to the CCGs, including recommendations on how the feedback should be used and developed to inform any proposals for change to existing respite services for people with learning disabilities by w/c 20 February 2017
- To make recommendations for further engagement activity to take place to inform development of any proposed changes to respite services for people
with learning disabilities, including formal public consultation if required by w/c 20 February 2017

- To ensure that engagement activity includes people from all groups with protected characteristics, as defined by the Equality Act 2010, and to validate perceived impacts (identified by the project equality impact assessment) on those groups that could result following any changes to respite services for people with learning disabilities by the end of the engagement activity period at w/c 20 February 2017.

4. Communications and Engagement Activity

As this is a review of specialist respite services, provided to people with learning disabilities, their families and carers, the initial engagement was restricted to those using these services already, potential users of respite services for people with learning disabilities and other relevant stakeholders (e.g. voluntary or private sector organisations that support people with learning disabilities).

If the review results in proposals that would mean substantial changes to the way respite services for people with learning disabilities are delivered or the types of services that will be available, this may result in the need for formal public consultation on those proposals. If formal public consultation is required, this process will be open to, and include, the wider general public and wider stakeholders.

The following table gives an overview of engagement activity that took place as part of the review of respite services for people with learning disabilities.

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<th>Activity</th>
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<td>Employment of a person with a learning</td>
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<td>The role of the two people on placement</td>
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| **Surveys for families and carers** | An online survey was created for families and carers (with printed copies available on request) with both quantitative and qualitative questions in relation to their experience of respite services for people with learning disabilities.

Information about the survey was sent to families and carers of people using current respite services, along with an invitation to take part in a facilitated discussion group. |
|---|---|
| **Facilitated discussion groups** | These discussion groups were facilitated by an independent voluntary sector organisation that has experience in supporting people with learning disabilities, families, and carers.

The aim of the discussion groups was to allow more in-depth exploration of the experience of people using respite services and their perceptions of how these could be improved.

The following formats of discussion groups will take place: |
- Discussion with people with learning disabilities
- Discussion with families and carers of people with learning disabilities
- Discussion with people with learning disabilities and families and carers together
- Discussion with people with learning disabilities within Bankfields Court, Normanby and Aysgarth, Stockton
- Discussion with representatives of voluntary sector organisations that support people with learning disabilities, their families and carers.

### ‘My Experience’ stories

A number of people that have experience of using respite services for people with learning disabilities were asked to tell their story. This will be used to inform the project and also, with permission, used in future engagement / consultation activity as a basis for further discussion.

### Co-production session to develop scenarios

People with learning disabilities will be actively involved in co-production sessions to develop potential scenarios for future delivery of respite services as the project progresses.
Co-production is a way of working that involves people who use health and care services, carers and communities in equal partnership and which engages groups of people at the earliest stages of service design, development and evaluation.

5. Who was Engaged

This initial, informal engagement was targeted at people with learning disabilities with complex needs, their families and carers who are existing users of health respite services, have used health respite services in the past or who could be potential users of health respite services in the future. Some engagement was also undertaken with representatives of community and voluntary sector organisations that offer support and advocacy services to people with learning disabilities and their families.

As the engagement activity involved face to face discussion with people with learning disabilities and complex needs, specialist voluntary sector organisations were commissioned to undertake the discussion group strand of the work to ensure that those taking part were given the maximum support and opportunity to have their say, with those facilitating the discussions having the skills and experience to facilitate effective communication with people with learning disabilities and complex needs.

In total, 206 people took part in the engagement activity. This figure is broken down in the table below. This represents a good response as the number of families currently accessing respite services is 91. [Is this correct?]
**Activity Type** | **Number of Participants**  
--- | ---  
Discussion groups with family carers  | 55  
Discussion groups with people with learning disabilities  | 50  
Joint discussion groups with family carers and people with a learning disability  | 9  
Discussion group with representatives of voluntary sector organisations  | 6  
Family and carer survey  | 86  
**Total**  | **206**

### 6. Analysis and Reporting

The engagement activity will result in a number of streams of quantitative and qualitative data.

As the data and feedback from those taking part in the engagement will inform the decision-making of the CCGs in relation to potential changes and developments to respite services for people with learning disabilities, it is essential that the data and feedback is subject to robust, in-depth analysis.

Depending on the size and complexity of the data, along with the timescale available for analysis, an external supplier, with expertise in this area, may be commissioned to conduct the data analysis.

This supplier will be identified as part of the engagement activity development process, and will be in place to begin the analysis before the end of the engagement activity if an external supplier is required.
A full engagement report will be produced at the end of the engagement activity.

This will contain an overview of the engagement, along with analysis of data and feedback from the perspective of people using, or potential users of, respite services and conclusions and recommendations for consideration by the CCGs. This will inform the decision-making process of the CCGs in relation to any proposed changes to respite services for people with learning disabilities.

The report will be published and widely distributed, to enable all stakeholders to see the results and recommendations. The CCGs will then make a decision on any proposals for changes to respite services.

If any proposals are made that could result in a substantial change to the current way respite services for people with learning disabilities are provided, this may then lead to the requirement for a period of formal public consultation. If proposals would not result in substantial changes to the way respite services are provided, another period of informal engagement may take place around the development and implementation of the proposals.

Whatever the outcome of the initial review, the joint overview and scrutiny committee of the four Local Authority areas will be kept updated and will give its view on whether or not formal consultation is required on any proposals for change that may come out of the review.

7. Main Themes from Engagement by Activity Type

7.1. Questionnaire for Families and Carers (main themes by question)

Question 1: What is your relationship to the person who has a learning disability?
• 80 people out of 86 answered this question
• 75 (94% of those who answered this question) described themselves as family members and 5 (6% of those who answered this question) were carers.

![Pie chart showing 94% Family Member and 6% Carer](chart.png)

**Question 2:** The word ‘respite’ is used by a lot of people, but means something different to different people, depending on who they are and in what situation they are using the word. Please tell us what the word ‘respite’ means to you as a family member, or carer of somebody who has a learning disability.

• 78 people out of 86 answered this question
• Common themes were:
  o Time for a short break and time to recharge batteries
  o Time to spend with family and friends
  o A place where the person can go and be happy and safe

A more detailed (anonymised) breakdown of what people said is given in Appendix 1.

**Question 3:** Do you currently use learning disability respite services?

• 78 out of 86 people answered this question
• 69 (88% of those who answered this question) people were currently using learning disability respite services at the time of the survey
- 7 (9% of those who answered this question) were not currently using any respite services
- 2 (3% of those who answered this question) were not sure.

A more detailed (anonymised) breakdown of what people said is given in Appendix 1.

**Question 4:** The respite services you use, are these provided for you by the NHS or Local Authority, or do you pay for them with direct payments?

- 41 (54% of those who answered this question) had their respite services provided by the NHS
- 19 (25% of those who answered this question) by the Local Authority
- 5 (7% of those who answered this question) from direct payments or Personal Health Budgets
- 11 (14% of those who answered this question) of people were not sure.
A more detailed (anonymised) breakdown of what people said is given in Appendix 1.

**Question 5:** How does access to respite services help you? For example, this could include things like being able to work, have a holiday or spend time doing other things.

- 76 people answered this question.
- Common themes that were:
  - Time for a short break
  - Time to have a holiday
  - Go out and socialise with friends and family
  - Get jobs done.

A more detailed (anonymised) breakdown of what people said is given in Appendix 1.

**Question 6:** How does access to respite services help your family member, or person you care for? For example, this could include things like being able to make friends, take part in activities they enjoy or learning new skills.

- 74 people answered this question
- Common themes were:
  - A chance to make friends/socialise
  - Learn important life skills
o Take part in activities and trips out
o Have a change of scenery

A more detailed (anonymised) breakdown of what people said is given in Appendix 1.

**Question 7:** How often do you feel that the current respite services you use meet your needs?

- 77 out of 86 people answered this question
- 31 (40% of those who answered this question) people said the service always met their needs
- 32 (42% of those who answered this question) said it often met their needs
- 11 (14% of those who answered this question) said the service sometimes met their needs
- 1 person (1% of those who answered this question) said their needs were rarely met
- 2 people (3% of those who answered this question) said their needs were never met.

**Question 8:** How often do you feel that the current respite services you use meet the needs of your family member, or the person you care for?

- 77 people answered this question
- 26 (34% of those who answered this question) people said the service often met their needs
- 36 (47% of those who answered this question) said it always met their needs
- 12 (15% of those who answered this question) said their needs were sometimes met
- 2 (3% of those who answered this question) said their needs were never met
- 1 person (1% of those who answered this question) said they were rarely met.
**Question 9:** Is there anything that you think we could do to make respite services better meet your needs?

- 75 people answered this question
- 42 people (56% of people who answered this question) said the services could be improved to better meet their needs
- 25 people (33% of people who answered this question) said there was nothing to improve
- 8 people (11% of those who answered this question) were not sure.
The main themes around what could be done to make health respite services better were:

- Making more respite time available
- Making arrangements for respite care more flexible
- Improving the standard of care
- Improving facilities from which respite services are provided.

**Question 10:** Is there anything that you think we could do to make respite services better meet the needs of your family member or person you care for?

- 73 people answered this question.
- 33 (45% of people who answered this question) said there was nothing the services could do to improve services to meet the needs of the person
- 28 (38% of those who answered this question) said the respite services could be improved
- 12 (17% of those who answered this question) were not sure.

**Question 11:** Have you had a recent carer’s assessment?

- 75 people answered this question.
- 34 people (45% of those who answered this question) had a recent carer’s assessment
• 24 people (32% of those who answered this question) had not
• 17 people (23% of those who answered this question) were not sure.

**Question 12:** If you answered yes, please tell us if your carer’s assessment identified a need for respite services.

• 38 people answered this question.
• 31 people (82% of those who answered this question) said their assessment identified a need for respite services
• 4 people (10% of those who answered this question) said their assessment had not identified a need for respite services
• 3 people (8% of those who answered this question) said they were not sure.
Question 13: Has your family member, or the person you care for, had any of the following assessments? Assessment of need that identified a need for respite

- 76 people answered this question.
- 51 people (67% of those who answered this question) had an assessment that identified a need for respite.
- 6 people (8% of those who answered this question) did not have the assessment.
- 19 people (25% of those who answered this question) were not sure.
Question 14: A continuing healthcare assessment which has identified that they have complex needs?

- 76 people answered this question.
- 57 people (75% of those who answered this question) had a healthcare assessment that identified complex needs.
- 9 people (12% of those who answered this question) had not.
- 10 people (13% of those who answered this question) were not sure.

Question 15: Does your family member, or person you care for, have specialist transport needs?

- 74 people answered this question.
- 53 people (72% of those who answered this question) needed specialist transport.
- 14 people (19% of those who answered this question) did not need specialist transport.
- 7 people (9% of those who answered this question) were not sure.
- Most of the specialist transport was for wheelchair users.
Question 16: Have you ever needed to use respite services in an emergency?

- 74 people answered this question.
- 56 people (73% of those who answered this question) needed to use respite services in an emergency.
- 19 people (25% of those who answered this question) have never needed to use respite services in an emergency.
- 2 people (2% of those who answered this question) were not sure.

Question 17: Is there anything that you think we could do to improve emergency respite services?
71 people answered this question.
16 people (23% of those who answered this question) said emergency respite services could be improved
22 people (31% of those who answered this question) said there is nothing to improve
33 (46% of those who answered this question) said they were not sure.

7.2. Discussion Groups with Families and Carers

Discussion groups with families and carers were facilitated by independent partners from the voluntary sector with expertise in support and advocacy for people with learning disabilities.

The overall process was overseen by Inclusion North on behalf of NECS. Stockton CAB and Skills for People engaged and supported people with learning disabilities, their families and carers and Inclusion North captured the views of representatives of Voluntary Sector Organisations who work with and support people with learning disabilities and their families and carers.

Full details of the discussion groups can be found in the reports from each organisation. These can be found in the appendices of this report.
The main themes from the discussion groups with families and carers were as follows:

**The Engagement Process:**

There was concern from family carers regarding the reasons behind the engagement exercise and some thought that it may result in respite services being cut.

People using respite services felt that their wishes are not always listened to with regards to respite.

Some people also felt that there needs to be consideration of ‘who’ respite is for when thinking about future provision.

**What Does Respite Mean to You?**

There was a wide range of views around the meaning of respite across the discussion groups, which made it apparent that respite means many different things to different people.

There were mixed views around whether or not day care activities should be seen as respite. The majority of participants felt that day care services are not respite.

There were also some comments about respite being delivered at home. The majority of participants do not consider that this type of respite would offer them a break.

Overall, participants felt that they needed further clarity as to what constitutes respite, as well as a central point for information outlining all the possible ‘respite options’ in each area. As well as being helpful generally, it was felt that this would offer individuals and families greater clarity and choice.

**The Benefits of Respite:**

Participants felt that respite services offered them a clear benefit. Many expressed a real appreciation of the services available to them.

Benefits identified included the opportunity for both parties to engage in different things, connect with other people and to have a break from each other.
Families and carers felt that it helped them to know that the health needs of their relative would be met and felt that they could trust staff.

Some participants said respite increased access to new opportunities and helped to develop greater independence for those using respite services.

Peer support for families and the opportunity to make friends for those using respite services were also considered important.

Participants emphasised that the impact of any proposals for change on the benefits of respite should be carefully considered before any changes are made.

**Resources:**

Participants felt that there was a general lack of awareness around how respite is funded.

There was also a perception that the use of personal budgets is more prevalent amongst younger people and their families and also in particular areas. For example, it was felt that there was a greater use of personal budgets in the Hartlepool area.

Some participants felt that confusion around funding could be difficult for families and that clarity around the funding process would relieve some pressure on families.

Staffing was identified as an issue for people who use personal budgets for their respite. Some participants felt this could be problematic and can impact on consistency of care.

Questions were raised as to whether wider community resources were equipped to meet the complex needs of people accessing respite services.

It was felt that a mapping exercise to identify what is currently available and where the gaps are might help.

**Suggested improvements to current health respite services:**

**Planning:** booking has to be done well in advance and has to fit with the routines of services rather than the individuals.

**Choice:** particularly for people with complex needs the choice of provision is limited, more beds should be made available.
Emergency provision: currently this results in cancellation of planned respite.

Coordination: this includes having a more coordinated approach for young people in ‘transition’, in relation to sources of funding, equipment and use of other resources.

Information: having a shared understanding of what ‘respite’ means and all the possible respite arrangements within this.

8. Conclusion

The engagement activity has provided a wide-range of data and feedback from families and carers and people with learning disabilities and complex needs. NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group and NHS South Tees Clinical Commissioning Group are asked to consider this data and feedback in determining whether current learning disability health respite services are best meeting the needs of those using them now and for the future.

Any proposals for change should be informed by the data and feedback from people with learning disabilities and complex needs, their families and carers.

If proposals for change are made, these should then be subject to further engagement throughout their development and implementation. If the proposals would result in a substantial variation to current health respite services, this should then be subject to formal public consultation before any changes are implemented.
Appendix 1. Anonymised Comments and Feedback from Family and Carer Survey [to be added following data anonymisation]
Respondents completing the survey were asked to answer the following questions:

**Question 1:** What is your relationship to the person who has a learning disability?

80 people out of 86 answered this question. 75 were family members and 5 were carers. This question was designed to find out the relation of the person taking the survey to the person with a learning disability.

94% of respondents said they were family members of a person with a learning disability. The remaining 6% said they were carers.

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<thead>
<tr>
<th>Relationship to person with learning disability</th>
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<tbody>
<tr>
<td>Family Member</td>
</tr>
<tr>
<td>Carer</td>
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<tr>
<td>94%</td>
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<td>6%</td>
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**Question 2:** The word ‘respite’ is used by a lot of people, but means something different to different people, depending on who they are and in what situation they
are using the word. Please tell us what the word ‘respite’ means to you as a family member, or carer of somebody who has a learning disability.

This was an open text response, and it was designed to find out what people’s different meanings of respite were. 78 people out of 86 responded on this question.

Common themes were:

- Time for a short break and time to recharge batteries
- Time to spend with family and friends
- A place where the person can go and be happy and safe

Comments from common themes included:

**Break**

“Respite to me means a break from looking after my daughter, knowing that she will be in good hands and taken care of.”

“Respite means a place where someone can go and be looked after properly, leaving the family to have some well-earned rest without having to worry. Respite is a much needed break.”

“It gives me a break from being a carer and the responsibility from it all. It also gives my son a break from me.”

**Time with family and friends**

“Respite to us meant time to enjoy ourselves, doing things like going to the cinema, out to dinner, meeting friends. These things may not seem much, but to us are much appreciated.”

“Respite means that I get a break and some freedom to go places I wouldn’t normally be able to go. It also means the person I care for gets a break from me and sees other people. This break makes them really happy.”

“The respite date calendar is the family coping framework for the year. Around those dates we plan times to come together and involve everyone from all generations to build family.”

**Safe Place**
“Respite to me means my daughter goes to stay somewhere where she is safe and happy. Also where her friends go too is important to her and me”.

“It means that our son is being well cared for, while we get the chance to recharge our batteries by having time out for ourselves. We know and trust the people who look after our son and we are happy to leave him with them at Unit 2 Bankfields”

“Respite means a place where someone can go and be looked after properly, leaving the family to have some well-earned rest without having to worry. Respite is a much needed break.”

**Question 3:** Do you currently use learning disability respite services?

This question was designed to find out how many people are currently using respite services.

78 out of 86 people answered this question. 69 (88% of those who answered this question) people were currently using learning disability respite services at the time of the survey. 7 (9% of those who answered this question) were not currently using any respite services. 2 (3% of those who answered this question) were not sure.
**Question 4:** The respite services you use, are these provided for you by the NHS or Local Authority, or do you pay for them with direct payments?

76 people out of 86 responded to this question. 41 (54% of those who answered this question) had their respite services provided by the NHS. 19 (25% of those who answered this question) by the Local Authority. 5 (7% of those who answered this question) from direct payments or personal health budgets. 11 (14% of those who answered this question) were not sure.
Question 5: How does access to respite services help you? For example, this could include things like being able to work, have a holiday or spend time doing other things.

This was an open text question with the objective of analysing how respite services help the carer/family member.

76 people answered this question.

Common themes included:

- A short break
- Time for a holiday
- Go out with friends
- Visit family
- Get jobs done
Comments by theme included:

**Short Break**

“I get some sleep which I don't usually get. My son gets a break from me. I feel refreshed when he comes back. I spend quality time with my partner and we see a movie or do something we can't usually do!”

“This gives me time for myself and also know that she is well taken care of during her stay. Something good for me. I can go away with peace of mind.”

“As I am in my mid-seventies respite gives me a very welcome rest and the chance to recharge my batteries. It also helps me to keep a positive outlook and makes it easier to cope with all the demands of caring.”

**Holidays**

“I am able to have a holiday knowing my daughter is well looked after and she enjoys going. Also, when I'm not well she can usually be accommodated, which is a great relief to me.”

“Respite helps to make it possible for us to have a holiday.”

“Having Aysgarth has helped me have the operations that I have needed over the past year and half, and a first holiday away, plus being a single parent it give me chance to get a break and to get some rest.”

**Socialising / Family Time**

“Mainly to continue caring for my daughter but also provide help for elderly family members, also spend some time doing things with my grandchildren.”

“Helps us have quality time as a family and do things we can't at other times, gives us opportunities to go shopping, cleaning, catching up with friends, get away for a couple of days.”

“It gives me a chance to catch up with friends and doing household things.”
Question 6: How does access to respite services help your family member, or person you care for? For example, this could include things like being able to make friends, take part in activities they enjoy or learning new skills.

This was an open text question with the objective of analysing how respite services help the person with a learning disability.

74 people answered this question.

Common themes included:

- A chance to make friends/socialize
- Learn life skills
- Take part in activities/trips
- Have a change of scenery

Comments by theme included:

Socialising

“My daughter likes the company of all the other clients and chats and laughs with them. It’s a lovely change for her.”
“Respite helps our family member make friends, and to know others apart from parents are able to care for him and for him to feel safe in their care.”

“My son really enjoys respite and looks for to seeing people he used to be at school with they take him to different places he really loves the staff as well”

**Skills**

“Depending on the type of respite available, respite can help my daughter retain her social skills, meet others in a similar position and if activities are available to participate to some extent. This increases her sense of wellbeing and self-confidence.”

“It gives my son the chance to meet new people and build up a bit of independence.”

**Activities**

“My son really enjoys respite and looks for to seeing people he used to be at school with they take him to different places he really loves the staff as well”

“A change of scenery and a chance to meet other people. Enjoying trips and days out. Taking part in fun activities.”

**Break**

“He gets a break from me. He loves company from other adults. He loves to sleep over at Baysdale; he thinks he’s on holiday”

“Gives son a break from usual routine, and opportunity to mix with others.”
**Question 7:** How often do you feel that current respite services meet your needs?

77 out of 86 people answered this question. 31 (40% of those who answered this question) people said the service always met their needs. 32 (42% of those who answered this question) said it often met their needs. 11 (14% of those who answered this question) said the service sometimes met their needs. 1 person (1% of those who answered this question) said their needs were rarely met. 2 people (3% of those who answered this question) said their needs were never met.
**Question 8:** How often do you feel that the current respite services you use meet the needs of your family member, or the person you care for?

77 people answered this question. 26 (34% of those who answered this question) people said the service often met their needs. 36 (47% of those who answered this question) said it always met their needs. 12 (15% of those who answered this question) said their needs were sometimes met. 2 (3% of those who answered this question) said their needs were never met. 1 person (1% of those who answered this question) said they were rarely met.

![Survey Results Chart](image)

**Question 9:** Is there anything that you think we could do to make respite services better meet your needs?

75 people answered this question. 42 people (56% of people who answered this question) said the services could be improved to better meet their needs. 25 people (33% of people who answered this question) said there was nothing to improve. 8 people (11% of those who answered this question) were not sure.
Is there anything that you think we could do to make respite services better meet your needs?

- Yes: 56%
- No: 33%
- Not sure: 11%

Common themes included:

- Improve care of clients
- Improve the facilities
- Be more flexible
- Have more beds available
- Have more respite time available.

Transforming Care: Review of Respite Services for People with Learning Disabilities and Complex Needs: Communications and Engagement Report
Question 10: Is there anything that you think we could do to make respite services better meet the needs of your family member or person you care for?

73 people answered this question. 33 (45% of people who answered this question) said there was nothing the services could do to improve services to meet the needs of the person. 28 (38% of those who answered this question) said the respite services could be improved. 12 (17% of those who answered this question) were not sure.

Common themes included:

- Better care of clients
- Improve respite centre facilities
- Improve transport services
- More respite time.
Question 11: Have you had a recent carer’s assessment?

75 people answered this question. 34 people (45% of those who answered this question) had a recent carer’s assessment. 24 people (32% of those who answered this question) had not. 17 people (23% of those who answered this question) were not sure.
**Question 12:** If you answered yes, please tell us if your carer’s assessment identified a need for respite services.

38 people answered this question. 31 people (82% of those who answered this question) said their assessment identified a need for respite services. 4 people (10% of those who answered this question) said their assessment had not identified a need for respite services. 3 people (8% of those who answered this question) said they were not sure.

![Chart showing 82% Yes, 10% No, 8% Not sure]

**Question 13:** Has your family member, or the person you care for, had any of the following assessments?

- Assessment of need that identified a need for respite.

76 people answered this question. 51 people (67% of those who answered this question) had an assessment that identified a need for respite. 6 people (8% of those who answered this question) did not have the assessment. 19 people (25% of those who answered this question) were not sure.
Has your family member, or the person you care for, had any of the following assessments? Assessment of need that identified a need for respite

- Yes: 67%
- No: 8%
- Not sure: 25%

**Question 14:** A continuing healthcare assessment which has identified that they have complex needs?

76 people answered this question. 57 people (75% of those who answered this question) had a healthcare assessment that identified complex needs. 9 people (12% of those who answered this question) had not. 10 people (13% of those who answered this question) were not sure.
Question 15: Does your family member, or person you care for, have specialist transport needs?

74 people answered this question. 53 people (72% of those who answered this question) needed specialist transport. 14 people (19% of those who answered this question) did not need specialist transport. 7 people (9% of those who answered this question) were not sure.

Most specialist transport was in relation to people who use wheelchairs. Most people had transport provided by the local council or the respite services.
**Question 16:** Have you ever needed to use respite services in an emergency?

74 people answered this question. 56 people (73% of those who answered this question) needed to use respite services in an emergency. 19 people (25% of those who answered this question) have never needed to use respite services in an emergency. 2 people (2% of those who answered this question) were not sure.
Comments people made about respite services in an emergency included:

“I was taken into hospital and my daughter was immediately taken into Aysgarth Respite where she was very happy to be.”

“We recently had a leak that left us without heating (still not fully fixed) and Bankfields were able to extend Ethan’s stay which was very helpful and we are really grateful for.”

“I have been in and out of hospital for the last few years, and without Bankfields Court and respite, I do not know how we would have coped, each time there is an emergency, I know I can ring Bankfields Court and they will help me.”

**Question 17:** Is there anything that you think we could do to improve emergency respite services?

71 people answered this question. 16 people (23% of those who answered this question) said emergency respite services could be improved. 22 people (31% of those who answered this question) said there is nothing to improve. 33 (46% of those who answered this question) said they were not sure.
Comments around improvements to emergency respite services included:

“Have at least one more bed available for emergency care”

“Make it more accessible for families to get respite. Have respite on night so I can have a break mid-week.”

“More information how to access emergency respite services and more places”

Responses to Survey Demographic Questions:

Do you consider yourself to have a long-standing illness or disability?

71% of people of those who answered this question did not consider themselves to have a long standing illness or disability. 29% of people who answered this question considered themselves to have a long standing illness or disability.

Do you consider yourself to have a long-standing illness or disability?

- Yes: 29%
- No: 71%

Transforming Care: Review of Respite Services for People with Learning Disabilities and Complex Needs: Communications and Engagement Report
Do you care for someone with a long-standing illness or disability?

93% of people who answered this question said they care for someone with a long standing illness or disability. 7% of people who answered this question said they did not care for someone with a long-standing illness or disability.

Are you pregnant or do you have a child under two years old?

97% of people who answered this question said they were not pregnant or did not have a child under 2 years old. 2% of people who answered this question preferred not to say. 1% of people who answered this question said they were pregnant or had a child under 2 years old.
**Are you pregnant or do you have a child under two years old?**

- Yes: 2%
- No: 97%
- Prefer not to say: 1%

**Have you undergone gender re-assignment?**

- Yes: 0%
- No: 98%
- Prefer not to say: 2%

98% of people who answered this question said they had not undergone gender reassignment. 2% of people who answered this question preferred not to say.
Ethnicity

- White British: 98%
- Asian British: 2%

Marital Status

- Married: 52%
- Single: 13%
- Divorced: 9%
- Widowed: 19%
- Separated: 0%
- Civil partnership: 5%
- Other: 0%

Sexuality

- Heterosexual/Straight: 94%
- Bisexual: 1%
- Gay or lesbian: 0%
- Prefer not to say: 0%
- Other: 5%
Appendix 3. Inclusion North Engagement Reports

Engagement exercise regarding respite services for people with learning disabilities and complex needs.

Summary Report

March 2017 by Kirsty Morgan, Project Support coordinator

Brief:

The Communications and Engagement Team of NHS North of England Commissioning Support (NECS) is supporting NHS South Tees Clinical Commissioning Group and NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group (‘the CCGs’) to actively engage members of the South Tees and Hartlepool and Stockton-On-Tees populations.

The aim of the engagement is to inform a review of respite services for people with learning disabilities (including complex needs) in the two CCG areas. This is to ensure that these services will appropriately meet the needs of the population now and into the future, in the context of the wider Transforming Care Agenda.

Delivery:

The engagement activities were delivered through the use of independent partners. Stockton CAB and Skills for People focused on capturing the experiences and views of people with learning disabilities and their family carers while Inclusion North looked to capture the views of Voluntary Sector Organisations who work with and support people with learning disabilities and their families in the respective areas. The individual detailed reports from this work can be found in the separate documents sent with this summary.

Engagement:

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<thead>
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<th>Who</th>
<th>Number</th>
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<tr>
<td>Family Carers</td>
<td>55</td>
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Summary Findings

Engagement & Communication:

There was concern from family carers primarily regarding the reasons behind the engagement exercise and a real fear that respite services would be cut. Continued communication with this group of people would be welcomed and offers an opportunity to enhance the further thinking regarding respite provision in this area.

People using respite services noted that their wishes are not always listened to with regards respite. There needs to be consideration of ‘who’ respite is for when thinking about future provision.

Meaning of Respite:

‘Respite’ means different things to different people. This was evident from the wide ranging discussion across all of the engagement activities as to what constituted ‘respite’.

There were mixed views in relation to ‘Day Care activities’ being seen as respite with the majority thinking this is not their understanding of respite.

There were again very mixed views about respite being delivered at home with most not considering this as offering the ‘break’ necessary and in some cases not having the equipment/resources to do so.

Clarity as to what constitutes respite and a central point for information outlining all the possible ‘respite’ options in the area, would be helpful and offer individuals and families greater clarity and choice.

Benefits of Respite:

The benefits of respite for all parties was clear and there was a real appreciation of the services currently available to support delivery of this.

The opportunity for both parties to engage in different things, connect with other people and have a break from one another were some of the shared benefits highlighted.

Knowing that the health needs of their relative would be met and being able to trust the staff were also of significant value to families.
Access to new opportunities and developing greater independence were important benefits for those using respite services.

Peer support for families and the opportunity to make friends for those using respite services were highlighted as being very important added benefits of accessing respite services. The impact on this of any potential changes needs to be considered.

Resources:

There was a general awareness as to how respite is funded. The use of personal budgets would appear to be more prevalent amongst younger individuals and their families and in particular areas, Hartlepool being one area identified.

It was noted that there can be debates regarding responsibility for respite funding and that these prove difficult for families to hear. Clarity about the process regarding this would negate this added pressure on families.

Staffing for people who use personal budgets for their respite can be problematic and where there is a high turnover of staff in some services this makes consistency of care difficult.

Location of respite was not a concern. A small number of family carers thought the Bankfield resource was perhaps no longer fit for purpose. Questions were also raised as to whether wider community resources were equipped to meet the complex needs of people accessing respite, for example changing places facilities and accessible shopping/leisure opportunities. A mapping exercise to identify what is currently available and where the gaps are may help when considering the overall ‘environment’ of respite.

Improvements:

There were a number of key themes which emerged from the engagement process which if addressed could improve people’s experience of respite further.

- **Planning respite**: booking has to be done well in advance and has to fit with the routines of services rather than the individuals.
- **Choice**: particularly for people with complex needs the choice of provision is limited, more beds to be made available.
- **Emergency provision**: currently this results in cancellation of planned respite.
- **Coordination**: this includes having a more coordinated approach for young people in ‘transition’, in relation to sources of funding, equipment and use of other resources.
• **Information**: having a shared understanding as to what ‘respite’ means and all the possible respite arrangements within this.

**Further Considerations:**

Within the more detailed reports there are a number of suggestions and examples of personal experiences which offer further insight into how respite services can be developed for the future.

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**Engagement with Voluntary Sector Organisations regarding respite services for people with learning disabilities and complex needs.**

Feb 2017 by Kirsty Morgan, Project Support coordinator

**Brief:**

The Communications and Engagement Team of NHS North of England Commissioning Support (NECS) is supporting NHS South Tees Clinical Commissioning Group and NHS Hartlepool and Stockton-on-Tees Clinical Commissioning Group (‘the CCGs’) to actively engage members of the South Tees and Hartlepool and Stockton-On-Tees populations.

The aim of the engagement is to inform a review of respite services for people with learning disabilities (including complex needs) in the two CCG areas. This is to ensure that these services will appropriately meet the needs of the population now and into the future, in the context of the wider Transforming Care Agenda.

**Method:**
8 Voluntary Sector Organisations, who work with and support people with learning disabilities and their families in these areas, were identified to take part in the engagement process. These were:

Stockton CAB, Skills for People, In Control-able, Hartlepool Carers Centre, Contact a Family, Middlesbrough CAB Advocacy Hub, Middlesbrough 1st and Sanctuary Housing.

Of these organisations 2 participated through a facilitated group session, 1 by a telephone interview and 2 through completion of a questionnaire. 1 organisation felt that direct contact with families through a separate engagement element would pick up the feedback they had to offer and 2 did not respond to the request to participate.

The same questions were posed to all organisations, the responses to these are detailed in Appendix 1.

Below is a summary of the main findings.

**Summary:**

What constitutes ‘respite’ is not clear and would benefit from further explanation. There is an acceptance that this means different things to different people but that this is not helpful in trying to support its best use. Having a resource detailing all the possibilities that ‘respite’ could be would be welcomed and offer a degree of clarity and choice to individuals and their families.

The importance of ‘respite’ to individuals and families was evident from the clear range of benefits identified for both parties. There were also additional benefits e.g. informal peer support, which are indirect benefits of respite.

Funding of respite provision was well understood. There would appear to be clear differences emerging between the uptake of personal budgets to fund respite on both a geographical and age basis. The additional responsibilities which come with managing a personal budget were cited as the potential barriers. Further exploration of this would be worth considering.

Trust from this community of people needs to be built, there is much anxiety around what the future holds. Communicating what has resulted from the engagement exercise would be an important first step in this process.

‘Transport’ issues and the ‘availability’ of respite were identified as two aspects which make the use of respite more difficult. Addressing these would offer a more positive experience for all involved. In addition to these consideration was given to respite in emergency situations. This often resulted in planned respite having to be cancelled so a better way of managing this would be welcomed.

There were a number of recommendations/considerations made for improving respite services, the detail of this should be studied closely. This evidences a clear
willingness from the wider Voluntary Sector Organisations to be part of the solution to improve respite services.

Appendix 1

Detailed findings:

1. The word ‘respite’ is used by a lot of people but means something different to different people depending on who they are and in what situation they are using the word. What does the word ‘respite’ mean to you?

There is no clear definition so it can be thought of as different things by different people. For example;

For the individual it can mean ‘doing something different’, ‘being sent away for a few days’, ‘a few hours out’, ‘having someone else to talk to’ or ‘support for them to access the local community’.

For the carer it can mean ‘bed based’, ‘freedom to attend appointments or do something different’, ‘their time’, ‘a break from constant care’ or ‘extra support in the mornings’.

Where people were able to define this they said ‘short break’, ‘a break from the caring role in terms of the carers, but a break from the routine and in some cases, the carer for people who access services’ and ‘the provision of alternative experiences for cared for persons to allow carers to undertake other activities’.

It was acknowledged that care needed to be taken if considering ‘Day Care’ as respite. Is this not what we all do during the day…. work, education and skill building? Respite is something different to this.

There was consideration of how ‘respite’ resources could be used creatively so not thinking in the traditional sense of the word. For example, having a cleaner so that ‘respite’ time wasn’t taken up with other practical responsibilities, so carers really could get a break.

Finally there was consideration as to whether going away together as family, with additional support could be considered respite.

2. What contact do you have with people and/or families who access respite services?
Work within a carer’s organisation, contact with those caring for a person with a learning disability is a small aspect of my role.

Daily contact with people with learning disabilities and their families through Advocacy, Self Advocacy, IMCA and DOLs.

Only meet people indirectly through the services we provide.

All others noted current contact.

3. What respite services are you aware of in the area covered?

Bankfield, bed based provision operating on a 2 weekly cycle; Orchard, community based offering day care; Aysgarth; Lanark, social care; Oak Road; Sanctuary respite service in Stockton; Caravan in Hartlepool.

There is some provision in other facilities which are otherwise residential (e.g. Longlast);

Aware of one to one arrangements for example, one of my clients stayed part of the time with a couple in Ingleby Barwick; another clients parents had an informal network of parents and their children with ASD.

Personal assistants being used to deliver respite.

Those highlighted on the Local Authority and Hartlepool Now websites.

4. What is your understanding of how respite services are funded?

Funded through Individual Budgets (direct payments and health), Continuing Health Care funding and Social Care. People are being encouraged to use their Carers Allowance to help pay for respite and some people are paying privately.

Respite is often funded under care and support on a case by case basis but authorities also fund some institutions on a grant basis.

Additional provision (such as the caravan, Holidays with Safe hands holidays, etc.) must generally be met from independent means e.g. parents, capital resources etc.

Would appear to depend on where you live. In Hartlepool it is primarily health budgets with only a couple of people accessing NHS respite provision. In Middlesbrough there appears to be a higher use of bed based provision and more reluctance to use an individualised approach.

Need to be mindful of the additional responsibilities with Individual Budgets for example; employment law, back up not built in, difficulties in recruiting and retaining staff, families having to ‘fit in’ with the availability of staff. It would appear that some carers think there is more ‘security’ of bed based respite provision as a result.
Under 25’s using education budgets to meet needs.

5. What do you see are the benefits of respite services for people with learning disabilities?
Opportunity to form new relationships with staff & individuals, mix with peers outside of formally structured activities, to be yourself, freedom, prevents social isolation, an opportunity to try/learn new things not readily available to you otherwise, develop independent skills and demonstrate your independence. A break from the routine and in some cases, the Carer for people who access services.

6. What do you see are the benefits of respite services for families?
Opportunity to be yourself, be seen as an individual, spend time with other family members or friends, reduce stress and recharge batteries, avoid psychological problems like depression, build up trust/reassurance with the respite service, prevent social isolation, opportunity to do something different, time to access peer support groups and a break from the caring role.

7. Are you aware of anything which makes accessing respite services difficult for individuals and/or their family? E.g. Transport to/from respite services
Transport is an issue. Bus journeys to/from the respite provision can be too long for the person to actually benefit from the respite. Transport is too expensive and in some areas (Hartlepool) adapted taxis are in short supply. People can use support transport but this may mean they are on this for a long time as the needs of other people accessing this have to be taken into consideration. Transport may not be available on the day/time you need it. Accessible transport and public transport timetables are a massive issue and barrier.
Access is an issue. Respite in the bed based provision needs to be planned in advance. There are no further days available if your circumstances change or there is an emergency. You have to fit with the 2week cycle at Bankfield. If using a personal budget you can be limited by staff availability. Can also be difficult to arrange respite at the same time as friends.

8. Is there anything you think could be done to improve respite services for individuals?
Personal budgets need to take into consideration the need to recruit higher skilled staff. It should not be the number of days/hours that is reduced to fit within the budget.
Consideration as to what support could be available in the community if additional support is required during a sleepover.

We have had some success developing a Self Advocacy group presence in Lanark and feel this would be useful in other formal respite premises both to aid the respite providers in developing services and help promote self-advocacy in general.

If people are going to make better use of their communities as part of their respite then they need these to be accessible, think about the availability of Changing Places facilities.

More choice and control over what people can access.

9. Is there anything you think could be done to improve respite services for families?

Online booking might assist.

More information to be available to families who don't want the person to have to go away.

More choice and control over what people can access.

10. Sometimes respite services have been used in an emergency. Is there anything which could be done to improve emergency respite services?

Not everyone has a Social Worker allocated so emergency situations are not always picked up straight away. Emergency respite is necessarily often associated with crisis situations and therefore often requires one-to-one fairly intense work. If this could be facilitated easily without a diminution of service to others this would be preferable.

The way the funding is set out you are not able to have a ‘bank’ of workers for such situations. The cost of emergency provision needs to be looked at e.g. A 3 day emergency stay could wipe out a person’s budget which would normally cover 4 wks. of day provision.

You may have to utilise an emergency offer in a different location. Where emergency services are a distance away from the individuals normal home a checklist of who to contact should be a priority.

You need to have money available to pay privately for these situations and not everyone is able to do this.

Greater awareness.
11. Anything else you would like to make us aware of in relation to respite services?

There is peer support available through some of the current provision so there needs to be investment in the community to maintain this invaluable support should services change.

There is still a need for 'bed based' provision for some people with higher health/support needs. There needs to be a range of respite options across all the locations. People need to know what is available, provision needs to be better advertised and the possibilities made real.

The environment of the respite provision needs to be considered. Roseberry Park, where there is a wide range of needs has more 'stigma' attached than say Bankfield which is known provision for people with learning and physical disabilities.

The focus should be on the fact that people are entitled to respite provision, not something they have to ask for.

People have been asked their opinions before, what is going to change? Feeling is they have had to fight for what they currently have. Really need to let people know what is going on.

Consideration needs to be given as to the impact of any changes. This should include the importance of routines to some people, friendships which have been built up and peer support for families.

Will there really be the opportunity for people with more complex/challenging needs, who may need 3:1 support, to have individualised respite packages developed?

Respite for the ‘family unit’ needs to be thought about as siblings of people with learning disabilities are often involved with the informal caring that’s required.

There are a number of activities that might reasonably be referred to as providing “respite”. A rolling list of such provision could be regularly circulated.

PA route seems to be the preferable option for younger people and families as there is a distrust of hospital & care services.

Clarity around who pays for an individual’s respite. Debates from Health & Social Care about who picks up the financial responsibility for an individual can be extremely difficult for a carer to listen to due to the focus being on what the person can’t do rather than what they can do.

Relationship with social worker is really important.
Appendix 4. Skills for People Report

Skills for People

Engagement about NHS respite services used by people from Hartlepool, Middlesbrough and Redcar and Cleveland.

On behalf of the North East Commissioning Support Unit

Through agreement with Inclusion North

February 2017

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Summary

Skills for People undertook engagement on behalf of the NECS through an agreement with Inclusion North, regarding NHS respite provision across Redcar & Cleveland. Engagement focused on adults with learning disabilities currently accessing respite provision, their families/carers and support providers. Skills for People widened the scope to engage those who may use respite provision in the future and their families and carers.

Engagement activity ran from 17 January - 14 February 2017. Links to online engagement documents were hosted on the Skills for People website and an easy read version was produced to aid engagement with service users. Information about the engagement, including details of engagement events and links to the online survey, was shared with both statutory and third sector organisations who work with adults with learning disabilities or their families/informal carers, and also with libraries and ward councillors. Events were organised in order to engage families/carers and service users at Bankfields, The Orchard and Kilton View.

All the views expressed here are those of people consulted: people with learning disabilities, family members/informal carers, and paid support workers.
**Stakeholder Engagement**

A communication strategy identified three key areas for stakeholder engagement: sharing of information with relevant organisations / individuals, provision of a minimum of 3 engagement events and 1:1 engagement where needed. A copy of the communications strategy is included at Appendix 1.

It was noted during the process that the most successful opportunities for gathering views came when Skills for People were able to engage with people via existing groups. Further notes on this and other aspects of the process are included in Appendix 2.

Events were planned in order to gather responses from service users and families/carers at Bankfields, the Orchard and Middlesbrough. These were planned with a wide variety of days/times. The following outlines the engagement undertaken:

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<tr>
<th>Area</th>
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*There were no requests for additional 1:1 support*
Redcar

People with learning disabilities were consulted in the following ways:

- Independent Voices, a group for adults with learning disabilities discussed the issues affecting them. Some members of the group have used respite services in the past but all are potential users of respite services in the future. One member of the group also has experience of using respite care as a family carer.
- Grenfell Women’s Group, a group for young women met and discussed the issues affecting them. Some members of the group have prior experience of respite care.
- Grenfell service users, a focus group with adults with learning disabilities. Some have used respite in the past and some access respite services currently.
- A community engagement event was organised at 25K Youth & Community Centre. This was widely promoted via community hubs and leaders but no one chose to attend.

Families/carers were consulted in the following ways:

- A drop in session was arranged at Kilton View in order to gather the views of families/carers. One family accessed respite at Bankfields.
- A community engagement event was organised at 25K Youth & Community Centre. This was widely promoted via community hubs and leaders but no one chose to attend.

Middlesbrough

People with learning disabilities were consulted in the following ways:

- An engagement event was organised at The Orchard where details of service user involvement in planning services and activities was gathered.

Families/carers were consulted in the following ways:

- 2 drop in sessions were organised at the Salvation Army hall, Eston in close proximity to Bankfields. Information was provided by Skills for People and shared by respite services. Bankfields staff encouraged attendance.
- 2 engagement events were organised at The Orchard. Information was provided by Skills for People and shared by The Orchard. No one chose to attend.
Hartlepool

People with learning disabilities were consulted in the following ways:

- Skills for People attended cafe 177 at a time when young people with learning disabilities attend. People attending were not current users of respite services but may become so in the future.

Families/informal carers were consulted in the following ways:

- Skills for People attended a family carers’ session at cafe 177 and provided surveys.
- Skills for People attended a carers’ meeting at Place in the Park to gather views.

Paid supporters were consulted as follows:

- Skills for People staff were available at cafe 177 which provides a hub for families/carers and service users with learning disabilities.

Service users and families/carers were consulted in the following ways:

- Skills for People engaged service users and families/carers on an ad hoc basis in a variety of locations. This allowed people who would not have otherwise been included in the process to present their views.

Engagement Responses – Emerging themes

The following gives the responses by theme.

Views expressed by families

The meaning of respite, the importance of respite:

The majority of families felt that the term ‘respite’ is a term that means overnight care. One family commented that they viewed day services as being about the service user (providing a positive routine) and overnight stays being about the family (providing a break).

Location of respite services does not seem to be a primary concern for families; it is the resources which are of primary concern, particularly for carers of adults with complex needs.
Care within respite is viewed positively across the board and it is the medical care which makes it possible for families to access and trust services. Without this level of trust families would be unable to feel their loved one is safe and happy, during these periods of respite.

For service users with complex needs, choices for families are limited. The services that are available fill a vital need and there is concern that even small changes could have an adverse impact on the quality of care affecting staff levels, staff continuity, access to transport and access to resources.

It was clear from conversations that families felt strongly that these services would not function without the levels of medical care currently provided and that there are no other services which could be shaped to replace them.

**Resources**

Respite care provides excellent access to positive experiences for service users with access to things like light and sound rooms. Families know there are times when they are at home when they would still like to use them. Currently, those service users who are not registered for respite services cannot access the resources. An option to ‘purchase’ the services for short periods would prevent resources sitting unused and give families much needed access at a manageable cost.

**Support for service users**

Some people use both overnight respite services, and respite during the day. One family raised concerns that, whilst home carers are able to remain with service users on overnight stays, this continuity does not continue into the day service. This can cause an interruption of continuity of care and raises problems for families when progress and good practice is not maintained across all aspects of care.

Routine is seen as important for service users and having a regular respite ‘slot’ allows service users to become comfortable with leaving families and also to ‘look forward’ to going. Because of this routine, service users were able to form relationships and friendships with each other and with staff. These relationships can last many years. For some service users, respite services are the only place where they socialise with friends and losing this would be devastating for these service users.

Whilst nursing/medical care is excellent, lack of resources has an impact on the time that can be spent on the more personal needs of service users. In respite services which have a high staff turnover there is little opportunity to build relationships which foster communication between staff and service users. Sometimes it is ‘knowing’ the individual as
much as medical knowledge which enables staff to spot problems and prevent them escalating.

One of the themes which came out strongly across both service users and families was the importance of respite having a ‘homely’ feel. People felt that smaller places helped provide the right atmosphere.

A large concern for one family was their experience of a gap in care between the ending of education provision and access to adult respite services. This was only bridged when parents fought for funding for provision. This gap could place a burden on families in a similar position who don’t have the confidence of the time/finances to fight for access. The impact on the service user is potentially detrimental and can effectively cut them off from social ties severely affecting their emotional wellbeing.

**Support for families/carers**

Respite services are providing additional support in navigating the system, getting referrals and appointments etc. One family raised a concern that this was not necessarily an efficient use of resources. Some families felt disempowered in planning care and accessing appropriate provision. Respite providers often help to resolve a problem or secures some support on behalf of service users/families. Families felt that staff from respite services get a speedier response than family members do when they raise similar concerns. Families are often under a great deal of stress and as a result can suffer more illness. Reducing the burden of families feeling they must fight for services; and responding to additional needs quickly may reduce the reliance of respite services to provide care in a crisis.

Families are aware that support is available from other sources but information is often sparse. Some hear of disputes between health and social care about funding for services, and feel that these organisations do not always work well together. Better integration of these services would reduce the burden on families to repeat information and limit the risk of different answers being given to the same questions.

A scheme similar to the hospital passports would also be useful for families who often have specific needs/circumstances which need to be taken into consideration when planning care and support.

Families felt that having the right staff in place within respite services provided not only reassurance but also a source of additional support in recognising and managing complex medical problems.

The concern that service may be reduced or removed places a huge amount of stress on families.
Respite is vital in allowing carers space to function as a family, experiences of working with carers at home is not always positive, particularly when using agency/unfamiliar staff. Again this raises the importance of staff having time to develop a relationship with the service user in order to be able to meet their needs. One family’s experience of home care was almost wholly negative with issues such as no continuity in staff, poorly trained/prepared staff and the need to take over care themselves when staff were unable to communicate. Additionally personal assistants and support workers often work with multiple service users so families find themselves working around the schedule of the support worker, instead of when and where support is really needed.

Support groups within respite provide a valuable peer support network for families and two families in Middlesbrough have carried on taking part following the death of their children because the groups provide a level of support and understanding that they do not find elsewhere. There is also a sense that respite services become part of family life and that families do not want to sever ties immediately.

One family had been involved in an external forum which was tasked to drive the agenda for respite care, this was felt to be too removed and ineffectual and it was suggested that an ‘in house’ committee to oversee the allocation of resources within individual respite services could do more to effect positive change and empower families.

For families there is sometimes a negative perception that comes with access to respite services: their feeling that they are being selfish by expecting their loved one to use respite services, can diminish the benefit for the family member.

An issue that was raised in Hartlepool was the need for more ‘drop-in’ services that they could access in a way which worked more flexibly with their schedules and responsibilities as a family. There is also a real lack of evening activities which precludes many working parents from the benefit of short breaks.

**Finance**

Direct payments can be useful at times but also place a burden on families who are not experts in this area and who are not always aware of what services/support is available/advisable. In addition to finance, families require impartial guidance on how best to use direct payments. Some families felt that it was easier to have budgets managed by the statutory service provided, meaning they feel more confident at the outset about what services they will receive. Direct payments were seen as a big responsibility for families with little support available to help them spend them well.

Some families have found it difficult to reconcile the strict requirements of respite services regarding equipment with their own needs as carers at home. Parents at Kilton view shared
their experience of wheelchairs which have to meet minimum requirements for transport but are too heavy and cumbersome for families to use at home. Many carers are older and can struggle with complex equipment. More flexibility in how vouchers (given to families to buy equipment) can be used to purchase equipment would be very helpful. An example of this is one family ended up purchasing an additional wheelchair that couldn’t be bought via voucher given.

**Community resources**

There is a lack of appropriate or accessible activities for adults with complex needs within the community. When the weather is good, people are able to access outdoor spaces but in bad weather options are limited.

Respite shouldn’t stop with day/overnight services, activities can be considered respite too. If service users were able to access leisure activities with support and appropriate equipment this would have a huge impact on the lives of service users. Families in Redcar and Cleveland shared there was a lack of acknowledgement from leisure services of people with complex needs and the resources needs, such as not having appropriate changing places, ramps, hoists etc. This includes the lack of a concession scheme for people with complex needs and their carers.

Centres like the Alan Shearer Centre provide excellent provision but are not within travelling reach of all families so a similar service closer to Teesside would be welcomed, it was also seen as important that any centre should focus on engaging the whole family not just service users.

Sometimes the needs and/or behaviour of service users stops them using universal services. Providing sessions similar to the supermarket autism only shopping nights would open up opportunities for service users to try things and access new experiences.

**Transport**

Transport provision is considered good although there are some concerns that services have been cut/and or will be in the future.

Higher transport costs and changes to transport timetables have an immediate negative effect, particularly on low income families or where there are school age children or working carers. (Parents may have to leave for work at a certain time, but are delayed when transport arrives late for example).

There is a lack of travel options available for families organising trips, appointments or activities for themselves. Respite services are taking some of the stress out of this by taking service users to appointments during their time in service but this takes valuable time away
from things which service users may enjoy. One family in Hartlepool found transport a
difficult issue, they accessed afternoon respite but with no transport provided, spent the
majority of time either travelling by bus back and forth from home (with only half an hour at
home before they had to return) or waiting near the respite service for pick up time. This
means no break for the family carer.

Service Users

The meaning of respite, the importance of respite:

Like families/carers, people who use respite services recognised the need to provide break
for carers and time for them to enjoy family life away from the responsibilities of providing
care. It was recognised it was important particularly those who are otherwise socially
isolated or in situations where a higher level of care is needed short term.

For some young service users there is still a sense of being ‘sent away’ whilst for other it
provided a welcome break from parental oversight and ‘nagging’. It was felt important that,
in order to be a positive experience, it was seen as their time to get away and ‘chill’.

Independence & Safety

It’s important for people to feel safe when in respite services. This requires staff to have
adequate and appropriate training but also knowing that other service users are not violent
or have criminal records. This is of particular concern to women.

People want to retain the independence they have at home. This could mean being able to
make decisions, travel independently or spend time with friends and take part in
leisure/work in the community.

Personalisation

One of the biggest concerns across all service users was being listened to. Too often it was
felt that respite was planned around carers’ needs but with very little concern for service
users’ needs and wants. Some people had had positive experiences but this seemed to be
entirely reliant on the ‘right people’ being involved. If service users are not involved in
decisions about respite care then it becomes very hard to trust staff and build relationships
with them. One service user had a negative experience as a young person of being simply
‘placed’ and found herself in a second floor room and, being unable to manage stairs,
became isolated – a simple conversation prior to placement would have mitigated this.
The environment can make a huge difference to how comfortable people feel. The positive effects of providing a homely atmosphere were raised. One group questioned whether ‘respite’ should always mean trying to create a homely space elsewhere, for service users with less complex needs respite could be provided in the home so people would be able to maintain their routine, independence and existing relationships.

**Being part of the Community**

For members of one group, respite gave them the skills to become more independent and respite service staff actively engaged in education about independent living. In particular, one service user had been part of the Moving On project which helped her become part of her wider community and make choices about her own life.

**Friendships & relationships**

People want to be able to develop friendships in any service they attend regularly. One of the issues face by one group was that of capacity and how they interact with people who have very different levels of communication. People want the chance to spend time with people of a similar age and with similar interests: there was an understanding that this isn’t always possible within services but they felt more could be done to engage them in peer groups elsewhere.

Service users, particularly young people, are able to learn about and build relationships within a safe environment, this includes the opportunity to develop adult relationships and partnerships. Being around other people with a similar experience gives people the space to be themselves and to take part in those ‘normal’ things they may feel excluded from within the wider community.

The Orchard supports individuals with complex needs, this made it difficult for some to communicate directly to us during the engagement and for those who could they were engaged in activities which they chose and enjoyed and did not want to break away from this. Staffs were able to provide information regarding how service users are able to make choices and drive the kind of care they want, and also what was available to support physical and communication needs. We were able to observe this for ourselves during each of visits.

Of the service users we engaged with, all also received support from additional respite providers.

- As with other services, The Orchard helps families by arranging appointments during respite time and providing staff and transport to appointments.
Physiotherapy is provided on site and Occupational Therapists are called in to assess each person’s needs. For service users this is essential as the equipment available is varied and specialised and unlikely to be available at home.

Activities are planned on the basis of service users likes/dislikes, particularly those activities within the community. Communication tools are used according to individual needs and these are used to build a timetable of trips/activities that meet everyone’s needs. On average, service users engage in community activities 3 days per week whilst using respite services, and these incur no additional costs for families.

The service closes for periods during school holiday times (Available only 2 weeks during the summer), the dates are provided to parents at the start of the calendar year so that they can arrange alternative care if needed and also so that service users can be emotionally prepared for changes to routine and social groups.

Direct quotes

“When I was in respite care I didn’t feel like my needs were taken into account, no one asked me what I liked” (Service user)

“I learned skills in respite which mean now I live independently but I didn’t always feel listened to” (Service user)

“We save the NHS lots of money by keeping people at home” (Family/Carer)

“There is a fear that if you ask for too much you could lose your child” (Family/Carer)

“When a parent finds something that works, you cling to it” (Family/Carer)

“Everything’s a fight” (Family/carer)
## Appendix 1: Communication Plan

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<th>Method</th>
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### Engagement Questionnaire

To make engagement information/questionnaire in a variety of formats.

- Carers/support workers of people of existing users of respite services
- Voluntary organisations supporting adults with learning difficulties

#### Engagement events

- **To hold 3 events (2 hours each)** bringing together adults with learning disabilities and complex needs to facilitate response to the engagement. We would expect that some will attend with family/carers to improve communication.

  - **Users of existing respite services**
  - **Carers/support workers of people of existing users of respite services**
  - **Adults with learning difficulties**

  - **Thought cloud**

**Engagement notes/report**

- **Engagement questionnaire**
- **Carers/support workers of people of existing users of respite services**

- **Voluntary organisations supporting adults with learning difficulties**

- **Collation of survey results**

- **Engagement events**

- **Users of existing respite services**

- **Carers/support workers of people of existing users of respite services**

- **Adults with learning difficulties**

- **Thought cloud**

- **Last week Jan 2017/first week Feb 2017**

- **Minimum of 3 during engagement**

- **List of attendees**

- **Project Worker/Lead Project Worker**

- **Audio/visual responses**

- **Collation of responses**

- **Worker**

- **Engagement notes/report**
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<th>Once</th>
<th>Meeting notes</th>
<th>Project Worker</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face to face engagement</td>
<td>To engage those who may not be able to participate through other channels. To provide opportunity for engagement response either individually or along with family/carers in a setting of the individual's choice.</td>
<td>Users of existing respite services</td>
<td>Meetings to be held at settings of individuals choice</td>
<td>As required</td>
<td>Ongoing</td>
<td>Audio/visual</td>
<td>Project Worker</td>
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<td></td>
<td>Carers/support workers of people of existing users of respite services</td>
<td>Adults with learning difficulties</td>
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<td>Meeting notes</td>
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<td>Adults with learning difficulties</td>
<td>Collation of responses</td>
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<tr>
<td>Engagement Report</td>
<td>To provide a full and accurate report of engagement activity, including</td>
<td>Inclusion North</td>
<td>Written report by 10/02/2017</td>
<td>End of engagement period</td>
<td>Written report</td>
<td>Project Worker/Lead Project</td>
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</tbody>
</table>
methodology and stakeholder engagement. To provide a full and accurate report of engagement responses.
Appendix 2: Notes on Process
Enabling person to a right...

So many...

By day...

Evening leaves it right...

Every day...

Of days...

Home big=
Skills for People NHS Respite Consultation February 2017 - addendum

O R C H A R D  S E R V I C E  U S E R S

UNIT 2 - 3.41 pm
LEVICK - 111

- Service user asked to engage but too busy in activity she chose & enjoyed.

- Visits person to person
  - Most people go elsewhere for work/leisure

Activities

- Light sewing
- Sketching
- Bricolage
- Play your own music
- Drama
- Parasailing

Physio is part of personal care
- Cannot cut on right
- Would you accept unless they come home
  - Most people unlikely to have activities at home
  - Anyone accessed by OT
  - Needs data can vary
  - Not an issue, but an option

- Activity based on individual needs

- E.自生/Concept care (placement)
  - Doctors would not on site - usually referred to FMS
  - Time-lag appointments

- 2 week response

Community-wide activities

- Planned well in advance
  - Friday, 10pm, 2nd week of calendar year.
What does Respite mean to you?

A break
- But a proper break. Don't have to worry if my daughter is safe.

Independence away from home

The relationship that are built and maintained

Safe environment

Opportunity for me to focus on my other daughter

Home from home environment

What are the Positives to Respite Provision?

- We want to be able to use out of cars break budget and know we'll not have to worry.
- It should be positive for me and elle.
- Having confidence that the place/people your returning child with

Butterwick
- Need to know the right professionals are on hand in case of a problem.

- My son's behaviour means he can always access the place - the respite venue has mental health support on hand. They go above and beyond.
what works well?

- Nursing care very good
- Own staff maintain good work - able to access
  - They support us in getting us to appointments
  - Community
  - They are plugging gaps in services

what isn't working?

- Skills not maintained in services - people not very knowledgeable
- Problems extend to home
- No physio - no safety net outside the service
- Needs right equipment (not having the right staff support)
- Giving choice - need the right mechanism (communication)
- Stafing levels
Skills for People NHS Respite Consultation February 2017 - addendum

...
Skills for People

Engagement about NHS respite services used by people from Hartlepool, Middlesbrough and Redcar and Cleveland.

On behalf of the North East Commissioning Support Unit

Through agreement with Inclusion North

February 2017

Addendum – Middlesbrough family carers engagement

24th February 2017

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Introduction

In response to concerns from family carers in Middlesbrough that they had not received adequate communication regarding engagement, Skills for People undertook a further session at The Cumberland Resource Centre, Middlesbrough.

<table>
<thead>
<tr>
<th>Area</th>
<th>Date</th>
<th>Venue</th>
<th>Stakeholders</th>
<th>Attendees</th>
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</thead>
<tbody>
<tr>
<td>Middlesbrough</td>
<td>24/02/2017</td>
<td>The Cumberland Resource Centre</td>
<td>Families/carers</td>
<td>3</td>
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</tbody>
</table>
Engagement Responses – Emerging themes

The following gives the responses by theme.

Views expressed by families

The meaning of respite, the importance of respite:

For the families consulted, respite is understood to be overnight provision only, noone viewed day services as respite care. When people are using overnight respite care and away from their families, the respite service is expected to deal with minor health issues and incidents, which relieves their family carers of these tasks, and allows the person and their family a good break away from each other. This break was seen as equally important for the service users. Day services on the other hand, provide a short break of only a few hours, and family carers are still expected to carry out these tasks, hence less of a break for the family.

All the families concurred with families previously consulted, that overnight provision is important in providing a necessary break for family carers, enabling them to ‘switch off’ and ‘re-energise’. This time was viewed as important for supporting other family relationships, particularly with other children and grandchildren and this was felt to be the most important outcome for the families. Many families use respite as a chance to relax at home and attend to domestic chores which are often postponed due to the responsibilities of being full time carers.

Because of the complex needs and/or challenging behaviour of service users social care cannot meet the same needs as NHS based respite provision.

All families were clear that respite at home could not take the place of current respite provision. Families felt they would not be able to have a break and ‘switch off’ from their caring responsibilities, if their relative and paid carers were in their home. Families understood that respite at home brings additional complexities when considering employees in the home such as providing sleeping space, insurances, equipment, supervision etc.

Resources

All families agreed that, in their experience, the current Bankfields site is no longer fit for purpose, it is considered old and outdated and one family had concerns about the cleanliness and hygiene levels possible with the current state of the building. Despite this staff are seen as ‘good’ and families feel the provision is acceptable and ‘better than nothing’.
Within some respite services, last minute changes to arrangements (eg late cancellation of
respite place, due to service being needed by another person following an emergency) can
cause problems for families and service users. Changes to staff on duty mean that there are
sometimes gaps in understanding of a person’s needs and triggers of their challenging
behaviour.

Families raised concerns about reliance on agency staff to provide support in the home.
Most families have contact with people who have struggled with agency staff, particularly in
relation to the inconsistent scheduling of visits, so that a support worker might arrive at very
different times of the day each week, which creates problems with being able to maintain a
cohesive schedule. Changes to schedules and staff often have an immediate negative impact
on quality of life for both carers and service users. One example was given where a person
had regularly missed doses of important medication through the day due to support staff
arriving at different times. These practices can mean families feel ‘trapped’ at home
waiting for support to arrive.

One parent raised a similar issue: their daughter needs 1:1 support when using a day
centre. Agency staff tend to be used by the council to provide this additional support.
Sometimes, when the parent arrives as the day centre, no supporter has been made
available by the agency, meaning the parent felt they had to stay with their daughter or
their daughter would not be able to stay at the service, and this would cause her distress
and associated ‘challenging behaviour’. This change to the routine can have negative effects
on emotional wellbeing.

Families felt that the system has an expectation that carers will ‘just get on with it’ – that
families will plug the gaps in provision because they have no choice.

Families expressed concern about the proposed development of Levick Court, a joint health
and social care facility. Families had welcomed this development and been consulted about
how it would work. Some service users had been supported to visit in preparation for their
future use of the service. The project was seemingly cancelled at the last minute but the
families had not been told of the reasons for this, but understand that the local health
service ‘pulled out’. This lack of communication has eroded faith in NHS services to include
families and carers in planning and decision making.

One family highlighted the issue of waste of resources which takes place when people are
due to use respite care, the service orders (and pays for) medication and incontinence pads
for the period of stay, despite the fact that families have access to free prescriptions for
these items. The outcome is that families have ‘stockpiles’ that they cannot share with
respite services and these services are spending significant amount of money on these same
resources. It was felt that this is not the best use of limited funding and could easily be
addressed with cooperation between families and service providers. Families had previously given this feedback, but no change had resulted.

**Support for service users**

There are concerns amongst older parents about what support will be available for their loved ones once they are no longer able to provide day to day care. More communication is needed between health/social care management and families/carers. Carers want to be involved in planning provision from the start so that any provision is fit for purpose.

**Support for families/carers**

The families noted that younger family carers seem less involved in discussing and influencing service provision, than older family carers have been in the past. Families were concerned about the impact on services in the future. It was felt this may be due to the difficulties in building relationships with staff if service transport is used. The introduction of daily record books at The Orchard has been welcomed as a positive tool for two way communication.

Families noted that changes to staff can make building relationships difficult and it was suggested that a newsletter could be used to introduce changes to provision and staff so that families did not feel removed from the services they use.

Bankfields hosts 3 coffee mornings a year for carers to come together. These are well attended and an extremely positive opportunity for people to come together for peer support and for issues to be raised/addressed. Families find the coffee mornings extremely positive. The Orchard have tried to introduce a similar programme which has never been successful, families were unable to suggest why this was the case.

**Finance**

All families felt that direct payments do not make things easier. As full time carers, families don’t want the additional responsibility of managing budgets, dealing with invoices and finding resources. One family had experience of things going wrong and dealing with managing an overpayment, where the local authority was funding a service when the person had a direct payment to pay for it. This took some sorting out. The challenging of budgeting to pay HMRC can be complicated. It was agreed that not all families have the confidence and ability to deal with direct payments and could face extreme difficulties in a similar situation. Employing home carers is a big responsibility and it is difficult to find regular trustworthy support workers. Using agency care is often seen as the only option but, it seemed that agencies often overwork their staff (e.g. only very short times to travel between visits to different people) and agency staff cannot be relied on to arrive on time. Families feel forced to put up with unreliable services because there is no alternative.
Emergency provision

All families have experience of planned respite being cancelled or of having to collect service users earlier than arranged. This makes it difficult for families to trust services and to plan their lives. Often other families step in to cover care where respite is cancelled but this places an undue burden on people who are already stretched to the limit. Families are happy to help each other and have a good support network but there is some concern that this creates an expectation among service providers that this will happen when services are unable to meet needs.

Current provision at Bankfields in particular doesn’t make it easy for carers to get emergency respite when needed. The system of alternate weeks for people with ‘challenging behaviour’ and those with complex needs means that carers can’t always get more than 7 days emergency respite at a time. One family sought respite support whilst one of the parents was being treated for a terminal illness in hospital. As respite could not be provided for more than one week, carers from other families stepped in to over support. One family mentioned a previous system which had been useful. When respite places were agreed, some would be definite while others would be liable to cancellation or cutting short in order to deal with an emergency. ‘Yellow letters’ notified the family if the respite booking was liable to cancellation. This made it easier to plan around respite and prevented last minute changes of plans by families.

Families felt that they had been assured of emergency provision when needed but now have less confidence that this is the case. Not trusting that respite is available in a crisis adds to the overall level of worry and stress for carers on a day to day basis.

In the past, ‘old peoples homes’ have been used for emergency respite cover. It was agreed by all families that this was inappropriate. In services which are not designed to manage complex care, staff are often unprepared and unable to meet needs of service users. People are more vulnerable in inappropriate settings. For families it is vital to know that service users are safe.

Response to Engagement Process

There were concerns that the length of time allowed for engagement did not allow enough people to engage meaningfully. The questionnaire wasn’t felt to be particularly relevant and it didn’t give scope for families to give the information they wanted to share. Families are happy, and eager, to engage at any stage because they want to be fully involved but feel that they are not always given the notice needed and that it is more useful to engage in a way which encourages open conversation rather than being constrained by questionnaires. Having the opportunity to actually talk through feelings allows for emotion and feeling to be part of the response.
**Direct quotes**

“Providers need to spend a day in the life of a parent carer” (Family carer)

“Healthcare provision should be provided by health services” (Family carer)
Flipchart notes from session
Appendix 5. Stockton Helps All Report

Transforming care:

Review of Respite Services for People with Learning Disabilities and Complex needs

Engagement activity conducted by Stockton Helps All

What does respite mean?

What works well?

How might it be improved?

February 2017

Authors: Anne Hollifield & Louise Lamont
Contents
1. Background
2. Findings
3. Next steps
4. Initial interview informing approach
5. Lanark: 25\textsuperscript{th} January 2017
6. Aysgarth: 25 January 2017
7. Lanark: 1 February 2017
8. Lanark carers: 3 February 2017
9. Aysgarth carers: 10 February 2017
10. Method
11. The sessions

Stockton Helps All

Stockton Helps All is a self advocacy group for Stockton residents with learning disability and learning difficulty. The group is supported by two self advocacy co-ordinators who conducted the group sessions.
1. Background

Stockton Helps All developed and conducted engagement sessions with service users and their parents/carers to address the following areas of interest from the specification document Review of Respite Services for People with learning Disabilities and Complex Needs, Andrew Robinson, December 2016, necs

‘The aim of the engagement is to inform a review of respite services for adults with learning disabilities (including complex needs) in the two CCG areas. This is to ensure that these services will appropriately meet the needs of the population now and into the future in the context of the wider Transforming Care Agenda.’

‘A period of informal engagement is being conducted to help the CCGs understand:

- What the expression ‘respite services’ means to people with learning disabilities, their families and carers
- What people with learning disabilities, their families and carers think works well with current respite services for people with learning disabilities
- How people with learning disabilities, their families and carers think respite services for people with learning disabilities could be improved.

This engagement will help to inform the development of a number of possible ‘scenarios’ for the provision of respite services for people with learning disabilities in the future. These scenarios will be ideas on how learning disability respite services could be further developed or delivered differently to best meet the needs of the local population.’

How we did this

We conducted 5 group sessions in all: 3 with service users and two with parents and carers as follows:

Lanark: 2 groups of service users, one group of parents/carers

Aysgarth: One group of service users

St John the Baptist Church: one group of parents/carers

The activities and materials used for the group sessions were co-developed with self advocates from Stockton Helps All.

2. Summary of findings
Total number of active participants = 30 parents/carers and 16 service users

Q. Who knows what respite means?

All the participants said they were familiar with the term and knew what respite meant.

Q. What does respite mean?

For most participants respite means an overnight stay away from your main carers. This was the view of 19 out of 30 parents/carers and 10 out of 16 respite users.

However there were many opinions regarding other service options that might be described as respite.

These included going away to stay at a caravan or camping. They also included being supported at home by a different carer if the usual carer was away.

6 service users at Lanark thought Respite could involve staying somewhere with your main carer.

1 parent/carers said that they also considered spending time together away from home as respite.

Q. What’s good about it?

- It’s a break on both sides
- Activities
- Continuity of staff
- Recharge our batteries
- Time to spend with other family and children
- My own room, own space

Q. What could be done better?

- More clarity about what is meant by the term respite. It means different things to different people.
- Relax rules about bed times and having to get up early
- No cancellations
• Better preparation for Transitions people so there are no gaps in service when the person reaches 18
• More outside activities for Aysgarth users
• Better communication about what’s proposed for the future
• Better communication about respite opportunities – for example the Primrose Hill caravan
• More beds to be made available

3. **Next steps**
We suggest that further areas for development should include:

• Produce report in Easy Read
• Report back to Service users
• Report back to parents
• Explore options for other forms of Respite Care other than staying overnight in a respite centre with parents and carers as they could not see how this could be possible within current constraints
• Further sessions with Aysgarth residents incorporating more time for participants to become familiar with the facilitators and the process

4. **Initial interview informing approach**
Notes from interview with Stockton Helps All self advocate to inform approach.

Q1. What does respite mean

* Lanark
  
  *Go for a break*
  
  *Get away from parents*
  
  *Not really need to stay over night*
  
  *Sometimes ok to stay over night*
  
  *But not all the time*

To stay overnight – where?
Could go to a caravan

To do activity?

? Someone could come to your house?

E.g. doing hair/nails?

? or when your carer is away?

Could the person be supported at home?

- Do as a story

What’s good at Lanark?

Doing own hair

Lots of activities

Knows other people

Lots of other people

Bad things

Hospital smell

Feels like ‘school’

People walking through the TV area

Less privacy

Rules e.g. 10 pm bedtime

Staff get you up at 7am

You don’t have the option of not getting up

Daytime activities

Wouldn’t call these respite

Reasons a person might go to Lanark

Main carer goes away

Main carer becomes ill

Not getting on so well at home
Like the evening activities

I want a break from home

Want to use the Den

My friend is going there

5. **Lanark 25th January 2017**

Lanark – 7 people – Wednesday 25th January 2017 5.30 pm

Q. Does anyone know what the word ‘respite’ means?

Yes – all 7

*Mam & Dad look after me at home*

*All the staff working here, when we go in the garden at Lanark*

**Choices at Lanark**

Q. Where could Respite be?

-Theatre, parties

*Pub, shops, read a book, shops, pictures, play football, on a holiday*

Q. Could Respite be at home?

6 – yes 1 – No

Prompt: - what about these activities (showing board)

*I love hair done*

*Cooking*

Prompt: Sensory room?

5 yes

Prompt: Football?

2 yes –I have a season ticket (gave seat details)

Prompt: Lanark?
7 yes

Prompt: pointing at activities

TV?

\[ I \text{ like the shops} \]

Sensory room?

\[ List\text{en to music – chill} \]

Go swimming?

\[ We\text{ go swimming at Lanark} \]

Prompt: Caravan?

\[-6\text{ yes 1 No} \]

Prompt: Camping? (a lot of noes)

\[ I’ve\text{ been before} \]

Prompt: Ideal respite?

\[ own\text{ bed, sink \& telly in your own room} \]

Q. Is Respite only when you stay overnight somewhere? 3 yes

\[ Not\text{ having my Mam \& Dad there} \]

\[ I\text{ like shopping at home sometimes} \]

\[ I\text{ like the Youthy, cinema, bowling} \]

Exploring scenarios

Scenario 1

Nick is the carer for Mike

Nick wants to go to America for a holiday

What are Mike’s options?

\[ Supported\text{ to stay at home = 6} \]
Mike’s choice’ = 6

Camping = no !!! (chorus of everyone)

Caravan = 5 yes, 1 no thank you

Friends = 5 liked

Carers = another carer can take him to football and the things he normally does

Scenario 2

NICK has to go in an ambulance to hospital where he has to stay for a period of time which could be one night, 2 nights or even 6 nights

‘Mike might go to a care home’

‘should be two beds in the hospital so he can stay in hospital with his carer’ = 4 agreed

‘What would happen if Nick got drunk and fell over and hit by a car and had to go to hospital?’

‘stay with other family’ = 7

Scenario 3

Julie is looked after by her Aunt – Marie

Julie wants to sleepover at her friend’s house

3 said this was ok, 2 said not

One person said a relative’s girlfriend sleeps over

Scenario 4

Julie lives with her mam

Aunt Marie is her main carer

Aunt Marie moves in with Julie and her mam so she can look after Julie all the time.

Is this a good idea?

6 people thought this was a good idea

Prompt: What could go wrong?

Prompt: what if Marie & Julie’s mam were arguing all the time?

Can live independently in Junction Road
Aysgarth 25 January 2017
Aysgarth – 7 people – Wednesday 25th January 2017 7pm

2 people actively participated. A further 5 were present but did not indicate preferences.

Q. Does anyone know what the word ‘respite’ means?

Yes = 2
Prompt: can anyone tell me?

‘Aysgarth’
Signed ‘here’ (pointing to floor and table)
‘Helping staff to tidy up’

Q. Where could respite be?

Camping? No = 2
Library? No = 2
Caravan? No = 2
Aysgarth? Yes = 2
Home? No = 2

Q. Which activities do you do at Aysgarth?

Watching TV Yes = 2
Sensory room Yes = 1 No = 1
Go to football No = 2
Hair & Make up yes = 2
Music yes = 2
Arts & crafts Yes = 2

Singing = yes! (care worker explained all clients there are very sensory)
Q. What about at home?

- Watching TV No = 2
- Go to watch football No = 2
- Arts & crafts No = 2

Scenarios

Scenario 1

Nick is the carer for Mike

Nick wants to go to America for a holiday

What are Mike’s options?

- ‘Like to come here’

Or

- ‘stay in his own house and have someone help him’
- ‘Yes good idea’

What about a caravan?

- ‘Yes good idea’

Other Activities?

- No response

Scenario 2 = we did not proceed with questions about the carer becoming ill as we felt this might be too distressing for the participants and we perceived people were getting tired

Scenario 3

Julie lives with her mam

Aunt Marie is her main carer

Aunt Marie moves in with Julie and her mam so she can look after Julie all the time.

- ‘think this is a good thing’

Q. What if they argued all the time?
Q. What if Julie wanted a break?

*Indicated Aysgarth as before – prompt: Aysgarth? here? = yes*

Q. (confirming previous answer) Could she come here for a break and leave them behind?

*(pause for thinking)*

= yes

*‘Could come here for a break’*

6. **Lanark 1 February 2017**

7 people

Q. Does anyone know what the word ‘respite’ means?

*Yes - 7*

Prompt: can anyone tell me?

*Come here to stay*

*Go out doing activities*

*Stay in and do activities*

*Go to the disco, the Malleable*

Q. Where could Respite be?

*Lanark*

*Oak Road*

*Hartburn [Elmwood]*

(prompt: pointing to pictures on boards)

*Caravan = 4*

*Camping = 6*

*Cinema (not respite = 1)*
You’re respite (pointing to facilitators Anne & Louise) = 1

Lanark & football = 4

Swimming at Lanark = 3

Who with?

Yes you can have respite with Mam and Dad = 6

Not with Mam and Dad = 5

Both = 5

All 7 agreed if you do activities from Lanark it’s respite = 7

If you do activities from home it’s not respite = 7

Respite – do you have to sleep over = 5

Sensory room in Lanark = yes

Snooker in Lanark = yes

Hairdressers in Lanark = yes

Gym at Lanark = yes

Watching TV at Lanark – not at home – is respite = 6

If you watch TV in your house it’s not respite = 6

Scenarios

Scenario 1

Nick is the carer for Mike

Nick wants to go to Australia for a long holiday to see his brother

What are Mike’s options?

Chill out

Work with someone else at his house

Mike’s day services might ask for fill in

Mike could stay with his family
Scenario 2

NICK has to go in an ambulance to hospital where he has to stay for a period of time which could be one night, 2 nights or even 6 nights

What are Mike’s options?

   A carer

   Family

   Could go and stay somewhere for example Portrack

Scenario 3

Mike lives with Nick but now Marie, his aunt moves in. Now there are arguments between Nick and Marie all the time.

What can Mike do?

   Tell somebody what’s happening

   Go in his bedroom

   Go on holiday

   Go to Lanark (respite)

   Going out for the day when you sleep at home is not respite (statement made by one participant – one person immediately disagreed)

   Somebody coming to your house to take care of you IS respite, but only if your parents are not there

7. Lanark carers 3 February 2017

Lanark Carers’ meeting – 6

Q. What does Respite mean?

   It’s a break for me and a break for her when she comes here

   She looks forward to it for days

   She asks when is she next going?
Q. Does it only mean here?

   No. There are other centres

   Then general discussion and agreement that people enjoy the activities at Lanark

Q. What about going out to do activities with a carer and them coming back home? Is that respite?

   - yes

   It’s a break on both sides

   And at the same time when they’re away we miss them. We always miss them.

Q. What about in a caravan with carers?

Doesn’t count as Respite?

   James Hadman, a professional from Catalyst said when he was talking about the Primrose Hill caravan he’d been told by carers to call it short break not respite

Scenarios

Carer goes to Australia for a month (planned break)

   Virtually impossible

   Need to give 4 months’ notice

   For honeymoon could only get short break

   I went away for 12 nights. My sister got 5 nights in Lanark – this was from our existing annual allocation. The rest of the time we relied on family

Carer suddenly goes into hospital for a week

   If there’s a medical emergency a team is supposed to kick in

   BUT my wife was the main carer for my daughter. She did everything for her. When my wife was dying from a brain tumour we only had 6 hours care a week for our daughter. So most of the time she came to the hospital with me

   I didn’t ask for help – to be fair

   We had no family

   No help was offered by anyone
We had a social worker but nobody offered help so our daughter had to come to the hospital all the time.

This was because my wife did everything for her so we had limited contact with day services and other sources of help.

Julie scenario – Aunty Marie moves in and arguments with mother persist

Julie could ask Social Worker

Julie could ask key worker

But only if she’s in day services

Many people have limited verbal ability

Some have limited non-verbal communication

My sister has very limited verbal ability – she couldn’t ask for help

Some people are not verbal at all

Some people don’t have contact with day services so how could they ask for help

Would they even know asking for help could make a difference?

8. Aysgarth carers 10th February 2017

24 people in attendance

This meeting was much larger than expected and many thought the purpose of the meeting was to feedback from the consultation and to propose changes to the service being provided.

This meant it was hard to steer along the same path as the previous discussions. Even though we put the same questions the discussion took on a life of its own which we recorded as the comments being made covered the areas we wanted to ask about.

Every time we have these things we lose beds

I know how you’re trying to do it, we appreciate that, but we’re worried about losing what we’ve got

We all got calls to fill the form in; they must be wanting to take things away from us

We’re all worried we’re going to lose respite
Q. Does anyone know what the word ‘respite’ means?

Yes = 24

Prompt: can anyone tell me?

Gives you a break

Stops us having to pay extra money

Peter enjoys it; it’s a break for Peter

He meets different people

Improves social skills

My son doesn’t sleep

Learn about independency

Interacting

Safe and secure

In a system being looked after

Another pair of eyes to experience the behaviours (that we see)

She has kicked off in there so people will now believe us about behaviours

Emergencies – health reasons

Operation – Got her in to be looked after

Had her in respite for her recovery and mine- after my cancer treatment

The main problem is the carer needs a break themselves

My son got planned respite cancelled because of an emergency

We want to spend time with our 3 year old grandchild

12 participants had had planned periods of respite care cancelled within the last year because of the place being taken by someone needing emergency respite

Aysgarth always give us the days back

You never ever get all of the days that you’re due

I disagree – we were called and offered extra days
(only one person reported this experience, however)

Q. Could respite be provided in the home? Has anyone experienced this?

*We had one-to-one support at home when in Hartlepool. However the support focussed on trying to get him to be independent and has now been taken away*

*We were asked about this two years ago – about him staying at someone else’s*

Q. What about staying somewhere else – pointing to choice board – what about the caravan?

*Primrose valley isn’t suitable for people in a wheelchair*

*A caravan isn’t wide enough for a wheelchair*

*My son is a runner – he can’t use Lanark – used one in Hartlepool*

*Every weekend we spend in the Primrose Valley caravan he’s always occupied – so his behaviours stop. We go with him – but we still get a break (it’s a break for all of us)*

Q. Did you know about the Primrose Valley caravan?

*Yes = 24*

Q. Is respite always a break from each other – or can it be an opportunity to spend time together away?

*Break from each other = 19*

*Spend time together = 1*

*I class the respite as us getting a break*

*I think it could be respite during the day (TASC)*

*Respite is set up when they’re children*

*If they start classing such as Allensway as respite we will lose the respite provided by day services = all 24 agreed and clapped*

Q. What do you like about respite?

*Continuity of staff*

*Recharge batteries*

*Time to spend with your other children*
Q. What do you not like about respite?

*Not enough*

*Need more beds*

*More Autism specific*

*More staff to take them out to do activities*

*Issues raised about classification of disabilities- dislike of ‘hierarchy’ of disability arising from having to demonstrate greater need than someone else*

*If they built another respite facility they’d save a fortune*

*With autism there needs to be continuity of carers*

*Transitions people – issues here as needs don’t change overnight. But they don’t sort out adult respite until they turn 18*

*This leaves a gap*

One person experienced 9 month gap

One person experienced 18 month gap

*They start thinking about it 2 years earlier but they still don’t sort it out until the last minute*

Q. How far ahead do you need to plan respite?

*A year ahead – used to be six months, even then you might not get it*

Q. How long could you go away for? What if you wanted to go away for a month?

*Only have 42 days a year*

*Can’t book anything to go away – you might not get the respite*

*You have to book the respite, then the holiday*

9. **Method**

The initial interview with one self advocate informed our approach which was further confirmed with discussions with another self advocate and carer.

The design of the sessions was done with participation and testing by Stockton Helps All self advocates.
The materials used including the selection and lamination of photos, and the shopping for materials, were done with the assistance of Stockton Helps All self advocates.

**Groups**

We designed the approach for groups of up to 8 participants as it was felt that in a larger group not everyone would have the chance to be heard. However the group session targeting Aysgarth carers drew 24 people and we were able to adapt our approach to draw and record contributions from most participants.

Lanark: 25\textsuperscript{th} January 2017 – evening - 7

Aysgarth: 25 January 2017 – evening – 2 active participants, 5 observing

Lanark: 1 February 2017 – evening - 7

Lanark carers: 3 February 2017 – morning - 6

Aysgarth carers: 10 February 2017- afternoon – 24

Participants were Stockton residents only
10. **The sessions**

We allowed 1 hour 15 minutes in total for each session, as follows:

- 15 minutes arrival and settling in
- 45 minutes engagement activity
- 15 minutes to allow for over-running if anyone wants to talk longer at the end

**Engagement activity plan**

- 10 minutes ice-breaking
- 20 minutes choice boards
- 15 minute scenarios

**Engagement activity detail**

- **Ice breaker:** participants can indicate their choices for activity in whichever way suits them best, including the use of Yes/no cards with thumbs up/thumbs down pictures which we will provide. The first part of the activity will explain this and practice indicating preferences.

  At this point it was stressed there were no right and wrong answers, and that each participant could have a different view from other people in the group.

- **Choice boards:** We used choice boards showing ‘location’, ‘activities’, ‘time of day’ and ‘who with’ to explore participants’ understanding of the term ‘respite’

- **Scenarios:** In the final segment we presented stories showing characters requiring respite care. Participants were invited to offer their opinions on what would be the best option in each case.

**Personnel:** Anne Hollifield led the sessions and Louise Lamont made notes of the discussions.