



## Short Breaks Review Engagement Report

January 2018

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## Acknowledgements

Hull City Council and NHS Hull Clinical Commissioning Group would like to thank all the parents and carers that took the time to complete a questionnaire or attend a focus group.

## Executive Summary

Hull City Council has a statutory duty to ensure a range of short break services are available to meet the needs of disabled children and young people to enable their parents and carers to receive a break from caring. NHS Hull Clinical Commissioning Group (CCG) supports Hull City Council in commissioning these services.

Hull City Council, NHS Hull CCG and Hull parents forum have jointly undertaken engagement with service users and potential service users of the short breaks services. The goals of this engagement work were to find out:

- What activities children and young people currently access to give them and their parents or carers short break.
- What barriers there might be preventing access to these activities
- How we can improve these services across the city.

1500 printed questionnaires were distributed to people who were most likely to access short breaks services. A link to the questionnaire was shared on social media, 301 completed questionnaires were received, 237 paper copies and 64 completed online. Four focus groups were held with parents and carers of children with special educational needs or disability; and were attended by 26 participants.

Based on Parent and Carer responses and feedback, the most accessed types of short breaks are those that are sporting. Activities in the holidays and respite / overnight are the next most accessed and in high demand. The majority of short breaks take place in a specialist setting i.e. one that would require a referral, the least in the community setting.

There is a large amount of inequity in the short breaks availability, 38% of respondents do not use short breaks; and of those who accessed a use short breaks half the adults feel it does not meet their needs, whereas 61% feel it meets their children's needs. Some parents and carers receive a good level of support to meet their needs; however some receive no support at all. The inequity is experienced equally as there no one group in particular that that is overlooked; this suggests an issue with the administration of short breaks, and the reach and availability information about short breaks .

Participants and respondents feel that accessing short breaks is a struggle, there are two key barriers to service; the first is lack of information about what services are available and how to access those services, for parents, carers, associated professionals and staff. The second is the range of assessment and referral process, parent and carer comments suggest this is complicated and takes time; although there are a range of assessments top access different short breaks at different levels and the process does not feel transparent.

From a parent and carer perspective; it is clear that short breaks services require improvement, specifically to improve access to services, and that short breaks meet the needs of those using them. Better information about the short breaks that are available, eligibility and how to access services needs to be developed with parents and carers; information also needs to be developed for staff and associated practitioners to support signposting. Although it is clear that

improvements to services need to be made, exactly what needs to be improved is not as clear. All negative comments related to the process of accessing a short break rather than the breaks themselves; how people are assessed and referred into short breaks services should be reviewed, and improved as a priority.

Any improvements to service should be informed by parents, carers, children and young people who are likely to use the provision in question. Half the people completing a questionnaire stated that they would like to be involved further. A co-production approach is recommended working with as many people as possible, employing techniques that do not really on meetings or face to face sessions due to the limited time available to those looking after children and young people with SEND. A client experience programme should be put in place to regularly review the short breaks provision and ensure they are improving to support the needs of families and young people.

## Reccomendations

This report makes 6 recommendations to inform future service planning and development

1. Short breaks provision requires improvement to expand reach and improve support.
2. There are three areas that require review and improvement as a priority;
  - i. Information relating to short breaks provision for parents, carers and professionals.
  - ii. The assessment and referral process and eligibility criteria for short break provision
  - iii. The capacity of short break activities in the school holidays.
3. Existing short breaks services, and those being introduced or developed should meet the needs of parents and carers, that have been highlighted during this engagement exercise.
4. The provision of short breaks by communities is low; this area of provision should be explored. Parent and carer contribution to services should also be explored further.
5. A clear plan for gathering experiences and views about short breaks needs to be developed. People accessing services should have a number of ways to give their views and experiences.
6. This engagement only looked at the views of parents and carers, service developments or changes should have a robust equality impact assessment to ensure that all groups are involved in ways that are appropriate for them.

# Introduction

“Local Authorities must provide,  
as part of the range of services they provide for families,  
breaks from caring for carers of disabled children  
to support them to continue to care for their children at home  
and to allow them to do so more effectively.”

Department of Education March 2011

Hull City Council has a statutory duty to make a range of short breaks services available to meet the needs of disabled children and young people to enable their parents and carers to receive a break from caring. NHS Hull Clinical Commissioning Group (CCG) supports Hull City Council in commissioning these services. Short breaks for disabled children can be provided by a wide range of organisations, including private and voluntary sector organisations. Many local areas have adopted a tiered approach, with targeted and specialist short breaks provided to supplement the universal services available to all children and families and this is an area to consider in Hull as part of the review of assessment and eligibility criteria that is being undertaken in January 2018

Hull City Council and NHS Hull CCG have been working with existing providers and the Hull parents forum through the short breaks steering group to review short breaks provision across the city. The goal of this engagement work is to understand:

- What activities children and young people currently access to give them and their parents or carers short break.
- What barriers there might be preventing access to these activities
- How we can improve these services across the city.

## What are Short Breaks?

Short breaks for children and young people with special educational needs and/or disabilities (SEND) come in many different forms and can:

- Provide opportunities for these children / young people to fulfil their potential through safe enjoyable experiences with or without their parent / carer
- Give parents / carers a break from caring, allowing them time to do day-to-day tasks, spend time with other family members, leisure activities or engage in education/training opportunities.
- Enhance the abilities of parents/carers to care more efficiently

Short breaks can range from a few hours, an evening, overnight, weekend stays or longer. They can occur during the day, the evening, weekends and school holidays and can take place in or out of the home environment, in the community or in a residential setting.

## Current Short Breaks Services

Short breaks in Hull comprises a range of provision across the LA, health and voluntary and community sector aimed at providing support for children and young people with SEND and their families to maintain children and young people in the home.

Not all children need or benefit from highly specialist services and many children with disabilities may be able to access community and mainstream provision such as youth clubs and after school clubs subject to the right support being made available with appropriately trained staff. A full range of services can be found as part of the local offer on webpage:

<http://hull.mylocaloffer.org/s4s/WhereILive/Council?pageId=3018>

When a family's needs are assessed, a social worker tries to find ways of making it possible for a child with special educational needs or physical disability to be looked after in the home. However, if the child is severely disabled or has learning disabilities/difficulties and needs or behaviours that are challenging the parents' or carers' ability to care for them, they may be assessed as needing a short or regular overnight break. Where children's needs cannot be met through existing community and mainstream provision Hull City Council currently commissions a range of specialist short breaks, in a variety of settings, to meet the needs of those children with disabilities requiring more intensive support

- Short breaks in a residential setting (e.g. Limetree Court, Kinloss Garth)
- Short breaks in a family setting (e.g. through direct payments or personal assistants)
- Family support and sitting services (e.g. through Barnardos or personal assistants)
- Short breaks in a health setting (e.g. Sunshine House, personal health budgets)
- Short breaks – day-care (e.g. sessions with Kids or LAFFS)

Children and young people's services and the CCG have some residential short break provision for children with disabilities and special needs who have been identified as needing this level of resource. This is currently accessed by assessment through Continuing Care or a Children's Social Care Assessment.

#### [Short breaks in a family setting and in the community](#)

Children and Young Peoples Services commission a short breaks provision from Barnardo's. Barnardo's recruit, approve and train carers to provide a stimulating family environment for a child with special needs. These carers are linked to children with disabilities and special needs and look after the child for short periods of time.

Some children and young people may have their needs met by the provision of a personal assistant (PA) who may be supported by a Direct Payment to support the young person away from the family home and to access social activities.

Specialist summer and out of school activities run by KIDS or LAFFS Youth services provide some short breaks social activities and the voluntary and community sector and schools offer social activities that aim to be inclusive for children with SEND. Sometimes this may involve specialist training and support for staff or the support of a PA to enable the young person to access these activities.

#### [Short breaks in a health setting](#)

NHS Hull CCG currently commissions a range of services that support short breaks services in a health setting. These include residential short breaks for children with disabilities and / or a caring need, examples include Sunshine House, Martins House hospice; referral to these services are usually from a health professional, but often social workers will be involved. Short breaks in a

health setting are also supported through children's continuing care funding, and personal health budgets provision.

Many short break support activities can be accessed without the involvement of social workers. However for the most specialist services a children's social care assessment will usually be required to, assesses the child's needs and the family circumstances. Based on that assessment, a multi-agency panel considers which service or services are best matched to these needs and the family's social worker will discuss the options with them.

## What We Know Already

### KIDS Yorkshire and the Humber

Throughout 2014 and 2015 KIDS, Yorkshire and Humber, undertook some engagement on behalf of Hull City Council and NHS Hull CCG. This engagement included the views of parents' and carers', children and young people, and service providers. The engagement used questionnaires, focus groups and one to one interviews.

The findings were mixed from parents' some of which were positive about specific services; others felt the service was not meeting their needs, the remainder not being aware of the services available. The majority of parents wanted support and services mostly during weekends and school holidays. Parents wanted short breaks to be provided by health/social care staff where this was in a facility, closely followed by personal assistants and they wanted personal assistants and/or family/friends to provide care in the family home.

Children and young people valued and wanted choice when planning and accessing a short break. They wanted; positive relationships with their carer/workers and predominantly wanted a regular, family worker who understood and knew their needs well. Weak or poor relationships had a negative impact on the health and wellbeing of children and young people. Young people felt it was extremely important that they were involved in the recruitment processes of their workers, specifically personal assistants. Children showed a preference for a parent/carer or family member to provide their care, in the family home and not overnight in a short break facility, whilst older children and young people articulated a desire to be cared for by a friend or someone outside the family unit. Young people wanted more opportunities to make friends and maintain friendships with a desire to have more independent short breaks. Children and young people wanted the same leisure opportunities as their non-disabled peers; including new activities, 'risky play' opportunities and fun experiences. The general consensus was that children and young people would like more short breaks, more frequently and for longer.

Service providers mirrored that positive personal relationships between themselves and the child/family were noted as key in delivering the service. Professionals highlighted a range of issues including access and criteria into services, limited choice, flexibility and levels of provision. The professionals who took part in this engagement were aware of the need to improve services and deliver a more tailored approach to children, young people and their families.

## Pupil Engagement Special Schools

Students from the following special schools; Ganton, Tweendykes, Frederick Holmes School and Northcott, took part discussions about short breaks. The discussions happened at their School Councils during May2017, and were supported using a prompt sheet. A follow up meeting was attended by 3 pupils and a staff member from each school representing the views of a wide range of pupils with cognitive, social and emotional and physical abilities.

### Summary of Discussions:

- The majority of pupils in all schools felt that they don't have enough opportunities to meet up with their friends outside school or to meet new friends 'like normal people do.'
- The after school clubs that are available are valued but present some difficulties, for example at Northcott and FHS you can only attend if your family collects you.
- Only a small proportion of pupils within each school access the after school clubs e.g. 20/140 at Tweendykes, 25/170 at Ganton etc.
- A significant number of older pupils felt they would be able to travel safely by taxi if 'someone puts us in and gets us out at the other end.'
- Holiday provision is valued by the pupils but again only available to a small proportion and not always with the activities that they would prefer.
- Almost every school had a number of pupils who would dearly love to access a Personal Assistant on a regular basis so that they could get out and about without relying on their family. They talked about examples where Pas had finished and no new PA could be found and how this felt: ' I was really isolated and annoyed' I became housebound and bored to death – it made me feel depressed' 'I felt trapped in my life and had to stay alone at home'.
- Young people would be keen to access mainstream services if they could have confidence in the ability of that service to manage them appropriately e.g. ' they would need to know how to talk to me' 'I would need help to manage my moods sometimes'.
- All schools had discussed overnight short breaks and felt these were really important for some families especially if the children were really poorly. They discussed this aspect with real compassion even when asked to weigh up the money spent on this as opposed to leisure activities for themselves.
- A small portion of pupils in all schools experience short breaks overnight with family members and really value this.



## How We Have Listened

Hull City Council, NHS Hull CCG and Hull parents forum developed the engagement approach with the Short Breaks Steering Group; a cross agency cross sector stakeholder group. Membership of the group consists of:

- Hull City Council
- NHS Hull Clinical Commissioning Group
- Hull Parents Forum
- Ganton Special School (representing special schools)
- City Healthcare Partnership (Community Children’s Health Services)
- KIDS Yorkshire and Humber
- Kinloss Garth Children’s Home
- LAFSS (Leisure and Free-time Support Service)
- Limetree Court Children’s Home
- Sunshine House

Although the engagement approach was co-designed, it was led by NHS Hull CCG engagement team and Hull City Council Transformation and Change Team. This was to ensure that the process was impartial and independent of existing services.

Hull Parents Forum has been involved throughout. This has included; supporting the development of the questionnaire, agreeing the focus group structure and content, setting up and observing the focus groups and reviewing the analysis approach. This level of involvement was to ensure co-production, and that the engagement process was transparent so that parent and carer views were; listened to, inform the review and development of short breaks services.

### Methods

The goals of this engagement work were to find out:

- What activities children and young people currently access to give them and their parents or carers short break.
- What barriers there might be preventing access to these activities
- How we can improve these services across the city.

To achieve the above goals two methods were adopted; a questionnaire and a series of focus groups.

### Questionnaires

The questionnaire and accompanying cover letter can be found in [appendix \(ii\)](#) on [page 4](#). The questionnaire was used to identify:

- Service awareness and barriers to accessing services
- To what extent short breaks services meet the needs of children, parents and carers
- Service preferences; including the types of activities and preferred timings.

Approximately 1500 printed questionnaires were sent out, about 1000 in book bags belonging to students at the following special schools; Tweendykes, Frederick, Northcott, and Ganton. 400 were

posted directly to parents whose child had an Education Health and Care Plan (EHCP). The remainder were distributed to appropriate groups as part of the day to day business of the children and families disability team, and a series of appropriate events. Respondents were asked to complete a survey for each child with Special Educational Needs and or Disability (SEND). A web link to the survey was shared by partners by email and through social media. The questionnaire was open from Monday 16<sup>th</sup> July 2017 to Sunday 3<sup>rd</sup> September 2017.

### Focus Groups

Focus groups were used to build upon the themes covered in the questionnaire in order to give insight into;

- What aspects of the current services are valued, and what could be improved
- What parents and cares want from a short breaks service
- The priorities of parents and carers to inform service planning and development

Four focus groups were held with parents and carers of children with special educational needs or disability, with 26 parents and carers attending in total.

- Friday 18<sup>th</sup> August 2017, 6:30pm – 8:30pm  
LAFSS, Belfield House, Middlesex Road, Hull HU8 0RB
- Thursday 7<sup>th</sup> September, 6:30pm – 8:30pm,  
St Ninians Church, Chanterlands Avenue, Hull HU5 4DJ
- Saturday 9<sup>th</sup> September, 11:00am – 12:30pm,  
Ings Library, Savoy Road, Hull HU8 0TY
- Monday 11<sup>th</sup> September, 1:00pm – 2:30pm,  
The Octagon Walker Street, Hull HU3 2RA

A further session was planned for Friday 8<sup>th</sup> September at Parks Children Centre; however this was cancelled due to nobody booking on to the session. People who completed a questionnaire were invited to be involved further; the focus groups were also promoted via NHS Hull CCG social media channels.

Anonymised transcripts of the focus group feedback discussions can be found in [appendix \(vi\)](#) on [page 26](#).

Each focus group followed the same format, three facilitated activities. In the first activity participants, working in pairs or small groups were asked to list things that work well and things that could be improved; this was an opportunity for people to get issues off their chest early in the session, and to gain insight into what people value in the current service based on their experience.

The second exercise participants were to complete the sheet in [appendix \(v\)](#) on [page 22](#); this asked what the participants got from a short break and what they would like to get out of one, what their children got from a short break and they would like them to get out of one. These type of questions may be very personal, sometimes participants may not feel they can share for fear of being judged; to avoid this, participants were asked to place their completed sheets in an envelope and seal them; this ensured anonymity enabling them to be honest. The responses can be seen in [appendix \(v\)](#) on [page 22](#).

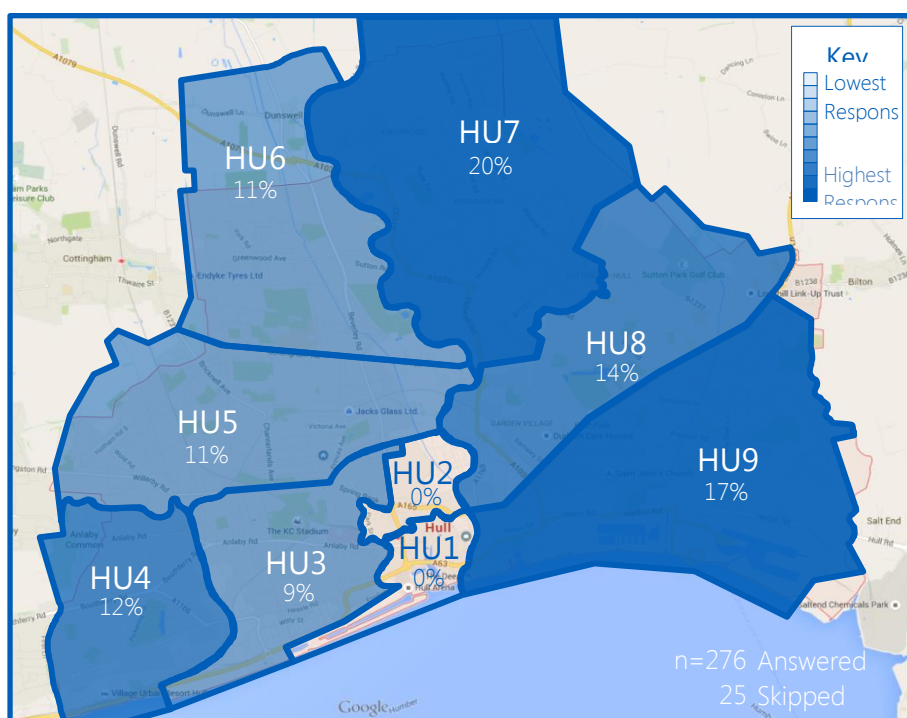
The third exercise involved participants listing aspects of service that should make up a short break, and then prioritising them into a bronze, silver and gold service. This gives an idea of what is important to service users, and indication of participant’s priorities.

Each participant was asked to complete a feedback form about the focus group, the full results can be seen in [appendix \(iv\)](#) on [page 21](#). Evaluation of the focus groups found:

- The majority of participants felt the aims of the session were clear, and that it was clear how their views and experiences will be used.
- The majority also felt that they had opportunity to give their views, and they were able to do this in a format that felt comfortable to them.
- Participants also felt that they had a chance to have their say and that they were listened to.

## Engagement Reach

1500 printed questionnaires were distributed to people who were most likely to access short breaks. A link to the questionnaire was shared on social media, 263 people on Facebook saw the post relating to the questionnaire, with 10 people following the link shared; on Twitter there were 7288 impressions, with 44 interactions; 23 retweets 11 likes and 10 clicked links. 301 completed questionnaires were received, 237 paper copies and 64 completed online.



◀ **Diagram 1**  
The number of respondents to the questionnaire by postcode.  
(n=276)

The full demographics of respondents can be seen in [appendix \(i\)](#) on [page 2](#).

The engagement activity making up this review was solely targeted at parents and carers, no children or young people were involved on this occasion.

Respondents were given the option to be involved further, of the 301 who completed a survey 152 stated they would like to be involved in the future. Those that expressed an interest in being involved further were invited to sign up to one of the focus groups.

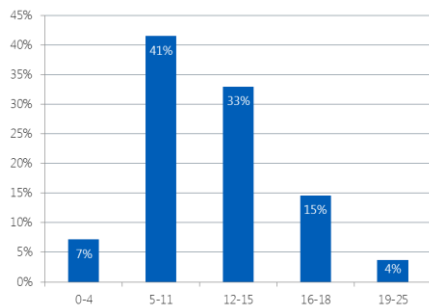
# Analysis of Feedback

## Questionnaires

The results of the questionnaires were analysed using the following cross sections; age, school type, and an indicator of need. The graphs below relate to the total responses, it is highlighted when one the above cross sections varies from the total responses. Free text responses can be seen in [appendix \(iii\)](#) on [page 10](#), these responses were coded and grouped by themes.

**Chart 1**

**Ages of the children of respondents**  
(n=295)

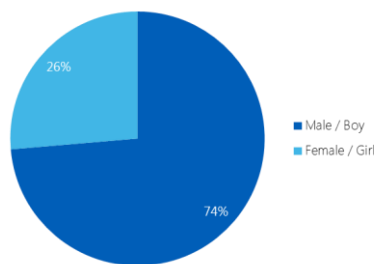


### Children and Young People

**Chart 1** shows the age distribution of the children of respondents, the age ranges align to local authority service age boundaries. School age (5-11, 12-15) is the largest category; this may be due to the fact that the questionnaire was sent out via schools.

**Chart 2**

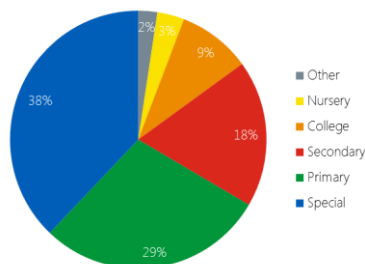
**The gender of the children of respondents**  
(n=296)



**Chart 2** shows the gender of the children of respondents; they are three quarters male to one quarter female; this reflects the SEND community that short breaks supports.

**Chart 3**

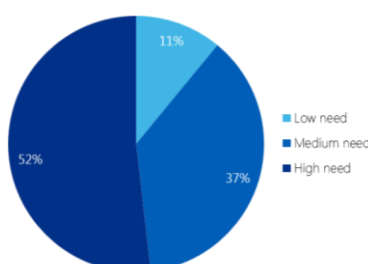
**The type of school children of respondents attend**  
(n=293)



**Chart 3** shows the type of school the respondents children attend, this is self-reported; over half of the respondents (59%) attend a mainstream school, with 38% attending a special school. Depending upon their needs, those attending mainstream schools may have additional support.

**Chart 4**

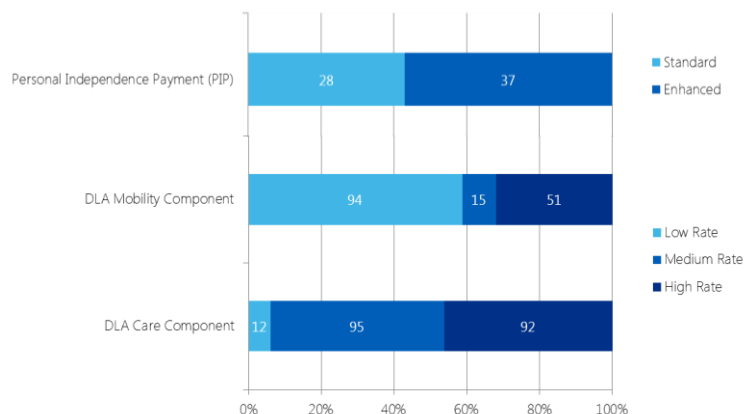
**Indication of need**  
(n=301)



**Chart 4** shows respondents grouped by an indicator of need, this was calculated using responses to question 5, which can be seen in [Chart 5](#), which asked whether respondents received Personal Independence Payments (PIP) or Disability Living Allowance (DLA). Those that did not receive PIP or any rate DLA were rated as low need.

**Chart 5**

**The SEND benefits being received by respondents**  
(n<sup>PIP</sup>=61, n<sup>DLA</sup>=251)



A medium rating was given to those in receipt of Low Rate DLA (mobility or -care), those who reported receiving medium rate mobility DLA were also included as DLA mobility is only high or low rate. Those receiving; High Rate Care Component, High Rate Mobility Component, and Middle Rate Care Component DLA or Enhanced Rate PIP for Mobility or Care were rated as high need.

### Existing Service

Chart 6

The types of short break currently accessed

(n=267)

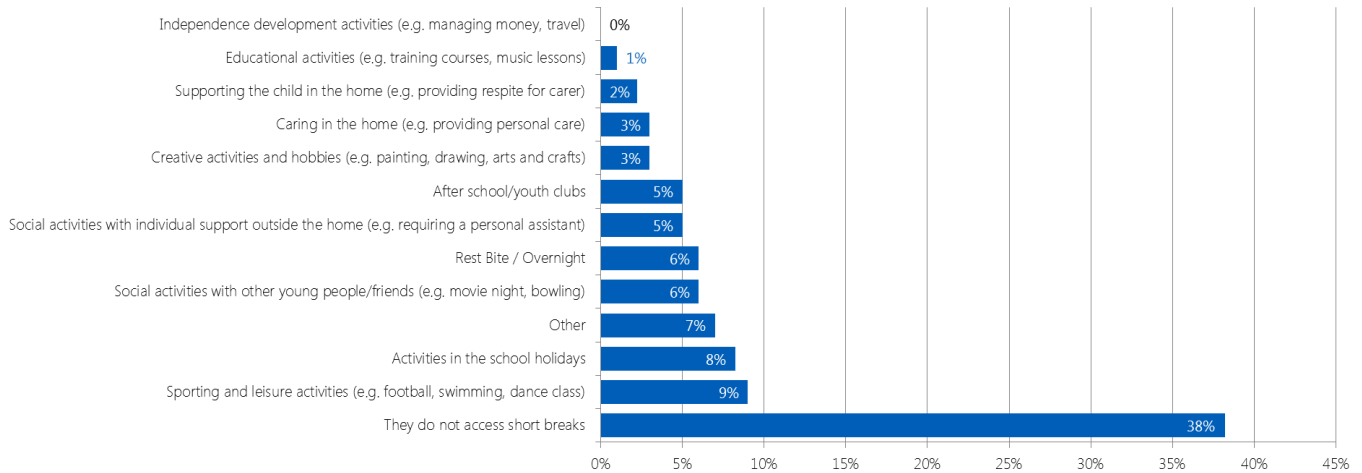


Chart 6 shows the types of short breaks currently accessed, the most accessed include sporting and leisure activities, activities in the school holidays. Social activities with other young people and respite or overnight breaks were the next popular; followed by social activities with individual support and after school clubs. The least accessed are independence development, educational activities, and support or care in the home.

38% of respondents stated that they did not access short breaks, although this was consistently the highest response from all age groups; about half (47.6%) of the under 5's and 5-11 year olds (47.6%) do not access short breaks. 45% of those attending mainstream education reported that they do not access short breaks, whereas 22.8% of those attending a special school reported not accessing short breaks. 35.7% of those with a perceived medium need, and 35.3% of those with a perceived high need reported not accessing short breaks.

Chart 7

The location or provider of short breaks

(n=120)

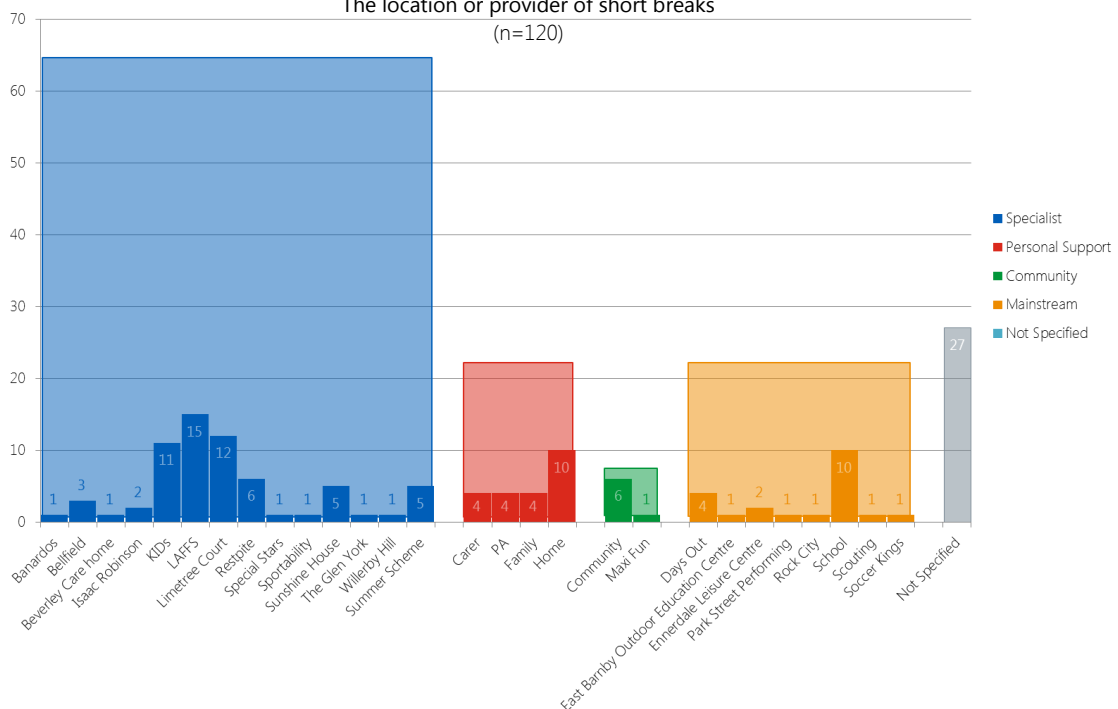


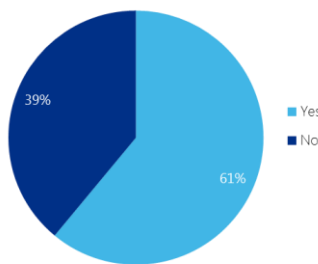
Chart 7 shows where the short break took place. Respondents named specific venues, providers and types of services, to make analysis easier these have been organised into 4 groups;

- **Specialist**, these are services that require a referral and take place away from the home.
- **Personal Support** includes, any support provided in the home, and support from a PA.
- **Community** is made up of community groups where no referral is required; it is like minded people or those in a similar situation working together.
- **Mainstream** are those activities or venues that are open to the general public, this may include adapted or supported sessions.

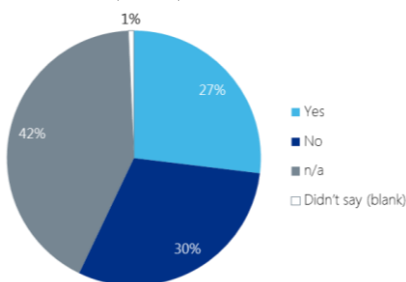
Please note these are not formal groupings or allocations, they have been grouped to demonstrate emerging themes or similarities.

The majority of services currently accessed fall into the “specialist” category, which require a referral and are formally commissioned. Mainstream and Personal Support are seemingly accessed equally. Community provision is accessed the least.

**Chart 8**  
Did the short break meet the needs of the child or young person (n=188)



**Chart 9**  
Did the short break meet the needs of parents or carers (n=214)



**Chart 10**  
The reasons respondents felt the short break did not meet their needs (n=124)

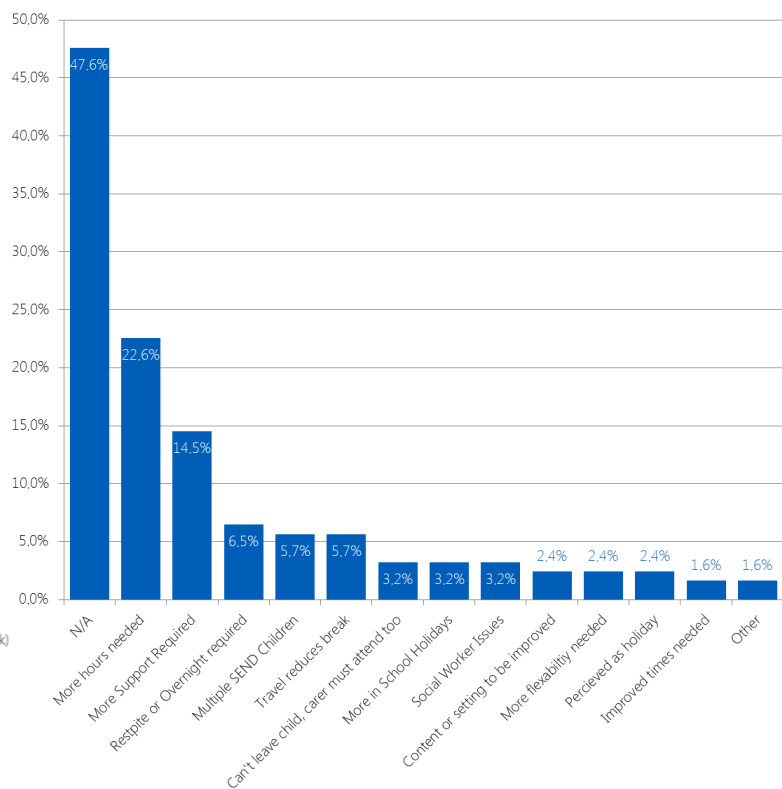


Chart 8 shows that 61% of respondents felt that existing short breaks met the needs of the children; however, Chart 9 shows that only 27% of parent or carers felt that it met their needs.

Of those that stated short breaks do not meet their needs 33.3% have a perceived high need, 31.3% a perceived medium need, and 12.1% a perceived low need.

Of the respondents that felt the short break did not meet the need of the children, 24.4% perceived high need, 26.8% perceived medium need, 18.2% a perceived low need.

The age group with the highest responses stating that the short break did not meet the needs of the child / young person was the 19-25 year olds (36.4%), this was also the highest age group where responses stated that the short break did not meet the need of the parent or carer.

The free text reasons why respondents felt that the short break did not meet their needs can be seen in [appendix \(iii\)](#) on [page 10](#); themes were coded and can be seen in [Chart 10](#).

The highest category of comments in the free text box where not related to the question, the highest pertinent response categories all related to additional support, the majority requiring more time, the next requiring more support the third requiring respite.

The next three most popular categories relate to the organisation of short breaks; families that have more than one child with SEND don't all attend an activity at the same time, meaning that the parents or carers don't have a break from caring for the other children.

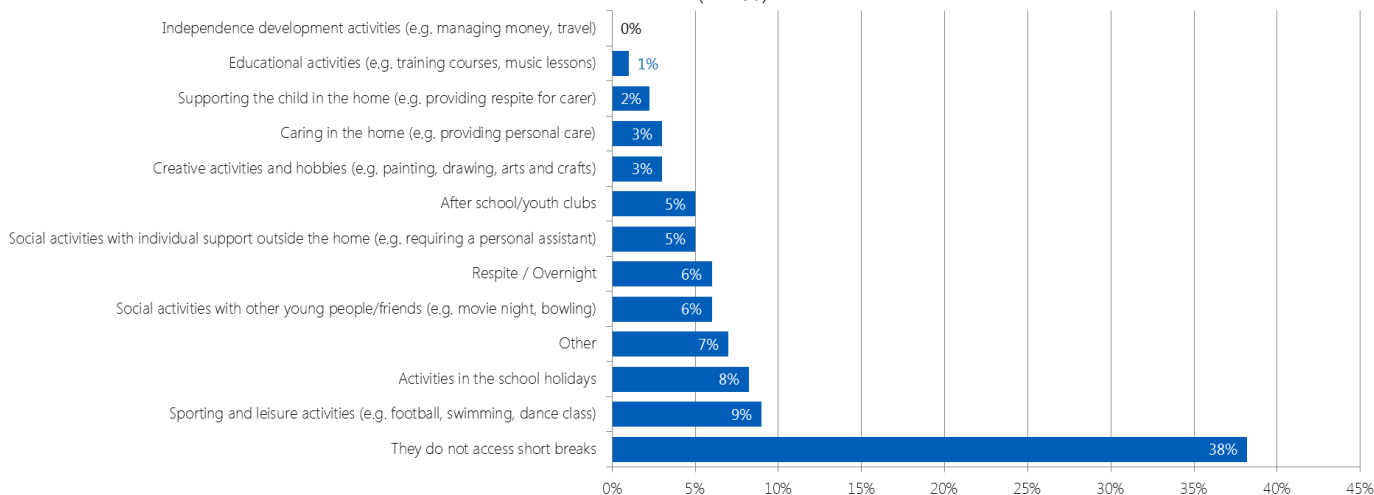
Travel to the short break reduces the amount of time the parent or carer spends away from the child, in some cases this results in the parent staying with the child meaning they don't always feel that they get a break.

## Service Developments

Chart 11

The types of short break respondents would like to access

(n=186)



Respondents were asked what activities they would like the children they care for to access as part of a short break, these free text responses can be found in appendix on page, they were grouped together into the categories previously asked in question 6, they can be found in [Chart 11](#). The most popular was "social activities with other young people / friends".

The next most popular where comments that could not be assigned to one of the groups, a number of themes can be seen in this category;

- People mistakenly assuming that short breaks are holidays or supported holidays for children and young people with SEND.
- Parents and carers wanting their child to be supported in accessing mainstream activities.
- Parents and carers wanting more local activities.
- Parents and carers wanting 1:1 support.

The third most popular category was sporting and leisure activities. The fourth most popular category was respite care, although this was not an option in the multiple choice question, there were a significant number of comments relating to the need for respite care to become a category.

**Chart 12** The reasons why respondents are unable to access their preferred type of short break (n=212)

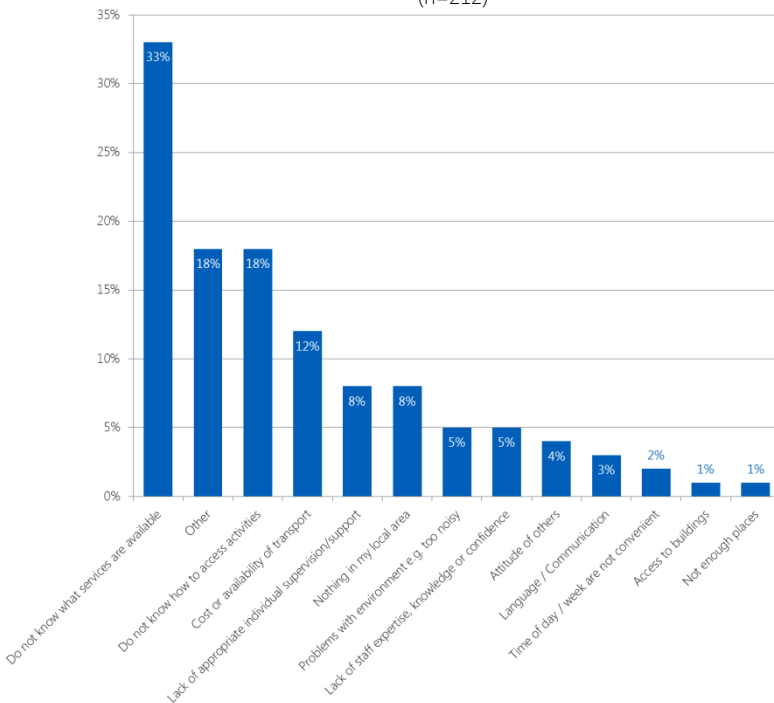


Chart 12 shows the reasons that respondents feel that they are unable to access the activities in Chart 11; over half of responses relate to not knowing what is available (33%) or how to access them (18%). 12% felt that the availability or cost of transport was a barrier to accessing activities; linked to this, 8% felt there was not enough provision in their local area. 8% felt that there was not an appropriate level of individual supervision or support.

**Chart 13** Comparison of the types of short breaks that are currently accessed, and the types of short break respondents would like to access

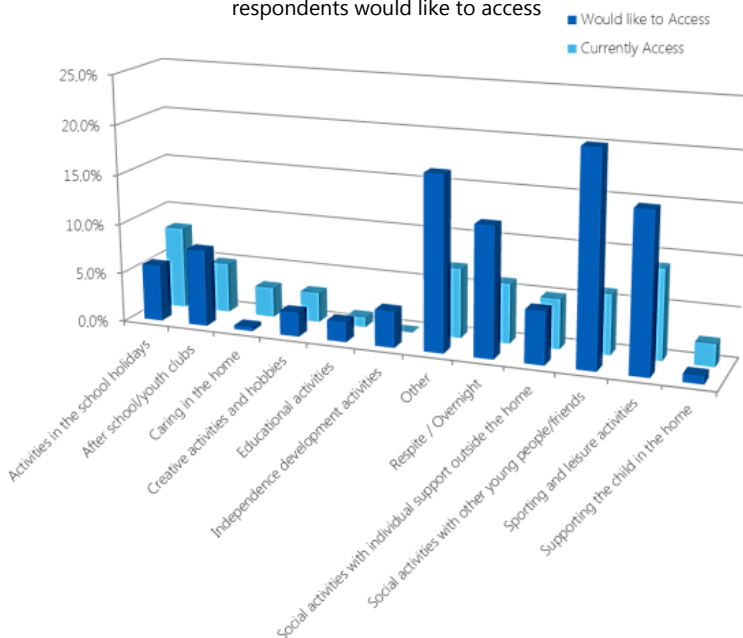


Chart 13 compares the categories of activity currently accessed and those that respondents would like to access, this may give an indication of where existing resource may need to be reallocated; however, there are more categories with an increase in potential need than those with less potential need and may suggest that more capacity may be required. This is only an indication of service requirement and would need further engagement with service users and potential users of service.



Chart 14

When would respondents like to access short breaks  
(n=232)

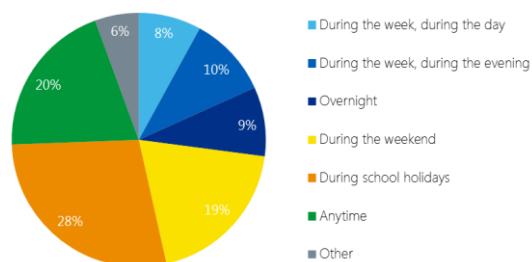


Chart 15

The number of respondents would be prepared to contribute to the cost of a short break  
(n=245)

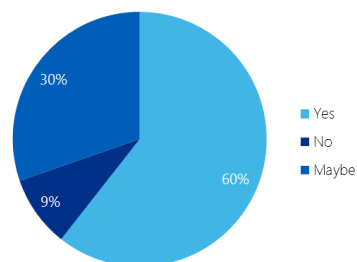


Chart 14 shows when respondents would prefer the short break, the two most requested times are linked to outside of school hours; during the school holidays (28%) and during the weekend (19%).

For those caring for children under five, anytime was the most popular result (23.8%); for those of school age, 5-11 and 12-15 would prefer provision in the school holidays (25% and 19.3% respectively). For the 16-18 age category the most popular choice was anytime (25.5%), for 19-25 year old age group the weekend was the most requested time (33.3%).

Chart 15 shows that almost all respondents would consider contributing to the cost of a short break, 60% answering “yes” and 30% “maybe”. This should be explored more thoroughly through supplementary engagement as part of any service development.

## Focus Groups

### Aspects of existing service that could be improved

Participants were asked to list things that were good about the short breaks and things that could be improved; this was done in small groups of two or three, then fed back to the wider group and discussed. Almost all of the negative comments relating to short breaks focus on the running or administration of provision as opposed to the services or activities themselves. The following are aspects of provision that could be improved:

- **Information relating to short breaks services;**  
A number of participants at each of the focus groups raised this as an issue. Not knowing what is available, and a lack of information was the main concern. Participants expressed frustration that they found it hard to access services because they didn't know what was available, or where to go to find out; when they managed to get in contact with services they weren't able to ask for particular support or services. "Nobody said how we had to find out, when you ring you get asked what you want rather than what they offer"
- **Difficulties in accessing services or support;**  
Participants gave numerous examples where they felt that system appeared to be obstructing access to the services they need, they spoke of a lack of support, a feeling of fighting for everything, with a lack of understanding from some professionals and related agencies. There was a feeling that decisions were budget or service lead rather than child lead; more about what can or can't be provided rather than what is needed. Linked to the above issues about information, participants felt there was not sufficient information about the eligibility for short breaks services, or how decision making works this led to a feeling that the process was not transparent. This was compounded by a feeling of contradictory reasons as to why people did not qualify, these included:
  - Being told that their child was "not disabled enough" for a short break
  - Because a family received Disability Living Allowance they were told that they would not qualify
  - Being told the child was too old for a social care assessment, and the process was so long that by the time they would have completed it, the child would be too old to qualify
  - Being told that a child was too old, or too young

Please note the above reasons do not align with existing assessment processes, nor would they preclude a child or family accessing short breaks provision.

There was a feeling at the sessions that the above reasons were incorrect. The same feelings were aired towards 'The Panel'. It was felt that the parent's corner wasn't being fought as well as it could be, and there was request that parents or an advocate be able to attend the panel discussion to make their case. "I feel like my life is dictated by the panel, even though things don't change we still have to go to the panel for a decision".

- **Complexity of services;**  
 Linked to difficulties in accessing services, participants found accessing short breaks and wider SEND services complex. In particular the paperwork that needs to be completed they found difficult, there was a feeling that they repeat the same information to multiple organisations and felt that there needs to be some kind of shared information sharing system put in place. They also found the system, multiple agencies, hard to navigate and made particular reference to the Department of Work and Pensions and GPs. There was a request for better support and signposting from diagnosis. The age boundaries for services added another level of confusion, which was an argument in support of better signposting at diagnosis, the fact that a child's ability age may differ significantly from their physical age was also raised as something to be taken into account. There was also concern that parts of the system were unaware of some of the complexities and challenges facing parents and carers. In particular the behaviour of some agencies may lead to parents and carers receiving half the hours that would be expected based on the allocation of supportive funding *"Some care providers charge £14 per hour and we're actually given a certain amount of money. I mean we pay £7.50 a little extra for tax and NI"*
- **Issues with Social Workers;**  
 There is a very apparent inequity with participants' experience of the social work team. *"If you have a good social worker you get loads, and if you have [a bad one] you get nothing"*. Participants felt the allocation of social worker seems arbitrary and that they must have a social worker to access short breaks services; with one participant being told their situation *"not bad enough for social worker"*. Those participants who do have a Social Worker have an inequitable experience, some feel they are helpful, however there are others who feel they are sometimes being obstructive, *"I get help for the other two but when I try to get help for the third I get cut down"*. A number experienced difficulties with the Social Workers being part time, and delays in assessments and poor communication *"they say they'll look into it and then never get back to you"*. There was also concern that the Social Workers don't have the specialist knowledge for dealing with SEND. It should be noted that all the Children and Families Disability Team, social workers and social work assistants, only hold cases of children who are SEND; and this possible misconception should be explored in future engagement.
- **Issues with services or activities;**  
 Travel and the location of activities were the biggest issue specific to services or activities. Participants from each of the groups had examples when they have taken their child to the short break and there not being enough time for them to return home or to have a break before they had to return to pick them up again, and so they have stayed; which in some cases defeats the object of the short break. A number of participants felt it would be better for short breaks to be located centrally, as it would make it easier for everyone to get to them, and some felt this would mean they would be able to use public transport, which in turn would help with the child or young person's independence. Some participants expressed a little frustration with the existing transport service, and that it can only take from home to school and back again, there was a feeling that it would be helpful if the transport was able to drop off at a short break service or child minder. Other issues relating specifically to the services or activities were that sometimes there is an inconsistency of staff or carers that cause disruption; and although the reasons were understood, when respite is cancelled due to

emergencies, and re-organisation can sometimes be frustrating. The need for more sessions in the school holidays was identified as an issue as they are always oversubscribed.

### Aspects of existing service that work well

Aspects of service that work well; there was less discussion about the aspects of provision that worked well; the comments have been broken down into two groups:

- Benefits for parent
  - Parents get a break; in particular overnight stays and 1:1 support were mentioned. *“Allowed to sleep like a normal person”*
  - Frees up time to spend with siblings
  - *“Direct payments have meant that I can continue my career”*
  - The opportunity to meet other parents in similar situations, supportive of each other, *“a lot of parents say that the best information they get is from each other, other parents”*
  - *“It is a big help in the holidays”*, when the lack of routine can bring its own complications.
  - Safe environment, with staff qualified to look after them *“we know that we can leave them and they’re happy with the staff so they’re not going to rebel and escape”*,
  
- Benefits for children
  - Enjoyment, experience things they may not otherwise, learn new skills,
  - Able to socialise, with kids in the same situation can be themselves, increase their ability improves social skills
  - Can highlight child’s abilities or interest in things that parents may not have considered
  - Helps them be more independent

### Expectation of Service

Participants were asked to answer four questions;

1. What do you get from a short break?
2. What would you like to get from a short break?
3. What does your child get from a short break?
4. What would you like your child to get from a short break?

Participants did this anonymously. The free text responses were coded to determine themes, and can be seen in [appendix v](#) on [page 22](#).

Response Theme	Frequency
Time with their other children	9
Rest or sleep	7
Time for household chores	6
Time to themselves	6
Time to socialise	4
Maintain mental health and wellbeing	4
Time with partner	2
The break benefits the child	2
Ability to work	1
Meet other parents in the same situation	1
n/a	9

◀ Table 1  
Themes from the responses to the question; what do you get from a short break?

Response Theme	Frequency
Time to themselves	6
Appropriate support	4
Rest or sleep	3
Time with their other children	1
Know the child is safe	1
The break benefits the child	1
Improve home environment	1
Time to socialise	1
Ability to work	1
n/a	3

◀ Table 2

Themes from the responses to the question; what one thing would you like to get from a short break?

The benefits listed in [table 1](#) could suggest that short breaks are meeting the requirement for short breaks provision, i.e. that the parent or carer has a break for caring to ensure that children with SEND can be cared for at home. However a number of the benefits listed in [table 1](#) also appear in [table 2](#), this suggests service inequality; that some people are getting what they need from the service whereas other are not, this is supported by people stating that they want “care or support” from the service.

Response Theme	Frequency
Socialising / Friends	21
New experiences	9
Independence	7
Fun, enjoyment	4
Own space, time away from parent / carer	4
Care or support	3
New skills	1
Improved quality of life	1
n/a	1

◀ Table 3

Themes from the responses to the question; what does your child get from a short break?

Response Theme	Frequency
Socialising / Friends	4
Fun, enjoyment	4
Own space, time away from parent / carer	3
Attend mainstream activities / to be like a normal child	2
New experiences	1
Care or support	1
Safe away from home	1
n/a	4

◀ Table 4

Themes from the responses to the question; what one thing would you like your child to get from a short break?

[Table 3](#) shows that the key thing the children gain from short breaks services is socialising and friendship, it also is an opportunity for children to experience new things and develop independence. [Table 2](#) shows that there is a desire for children to be supported to attend mainstream activities.

Both [table 2](#) and [table 4](#) have a reference to safety, this suggests a need for reassurance that services are able to appropriately support the child's needs, and that this is communicated to parents and carers.

### Aspects of Future Service

Using the analogy of a hand car wash, which offers Bronze Silver and Gold service, participants were asked to describe the ideal short breaks service in the same terms. The Bronze service being the essential basic package, the silver including everything that the bronze offers with some extra benefits or services, and the Gold service that includes everything from the previous two grades plus or service.

#### Bronze Service:

- A rest for the parent or carer.
- Fun for the children.
- The providers need to be understanding of the children's needs. Parents need to be able to trust the people who are looking after the child or young person.
- Staff.
  - Should be DBS checked.
  - Should be properly trained.
  - Staff training programme.
  - Fun entertaining an engaging staff.
- Allocated Social Worker that is a good fit, so can change if needed.
- Good assessment at the beginning, with subsequent assessments building on, or referring to previous.
- The package needs to be tailored to the family situation, if it isn't it is unlikely it will benefit the family, some flexibility required.
- Consistency of service and staff.
- Access to an advocate.
- Support to access mainstream activities.
- Crisis support from someone who is aware of SEND needs and services the end of a phone

#### Silver Service:

- Involve the sibling(s) with or without SEND, if appropriate.
- Taster sessions, for new experiences, leading to funded or partially funded activities

#### Gold Service:

- Sustainability, it's an ever changing landscape due to the nature of funding activities and services appear and disappear, it is hard to get them to try new things particularly if the disappear as they get used to them.
- Carer support on holiday
- A part funded Family Break together
- A SEND Summer camp for couple of days and nights in the summer, similar to the American summer camp model

Two aspects of service spanned all three categories; travel and time. For some participants travel being part of the service was seen as an essential, "[You've got to get them there](#)". Others felt that

travel should be part of the silver service, “some kind of deal, not everything has to be provided by the council” as part of these discussions central locations were preferred to make public transport travel easier, or very local services or activities eliminating the travel need. Another suggestion was that short sessions should have transport provided to ensure that the parents or carers get a break, but longer sessions wouldn't need travel included as there would be time to return.

Time was also placed in more than one category; it was felt that a short amount of time to do basic things like sleeping, shopping etc. should be part the basic bronze package, following discussions around use of time it was concluded that longer breaks would put them into the silver and gold categories, also the frequency would determine whether the break was a bronze silver or gold session.

Age groups were discussed but no agreement reached about placement, there was some suggestion that services for school children should feature in the bronze, Teen 16-18 the silver, and 19-25 gold; based on the fact that 19-15 year olds would be transitioning into adult services, this form of allocation was disputed as physical age and ability age are very different, “[anon] is 16 but got the social understanding of a 6 year old but he doesn't want to do the six year old stuff, [...] is he going to be 16 today or 6 or 12?”

There were some service principles that were discussed but not allocated to a package, these were:

- Plain English should be used throughout SEND services, words that are simple and easy to understand.
- Families should have the ability to have a review when required, and they should not be left until they reach breaking point
- One form held at the council, with all information on, which should be shared where and when appropriate with other agencies. Better communication between agencies and groups
- More flexibility with direct payments, and support in using them

## Engagement Quotes

Throughout this engagement process something that was referred to in passing a number of times was that parents and carers of children and young people with SEND feel that people do not understand what it is like to be in their situation. The following are quotes from this engagement that give insight into what is like accessing short breaks services and generally living with and caring for children with SEND, and highlight some of the themes already discussed.

“Some people say, ‘Well, you’re the parent, anyway.’ So, why do you get carers when you’re the mum and dad? I’ll tell you what? I’ll move in yours, you come in mine for a week and tell me then. My friend did it once. She came and lived with me for a week, one of my best friends. And her words was, ‘don’t ever [*expletive*] ask me to come and stay with you again’. That was her words to me. She said, ‘That was one of my hardest weeks I’ve had to do’.”

“[Normal people] you do a 12-hour shift, we go to our job, and we come home and we’d rest and we’d eat and we’d sleep and interact and everything else. But as full time carers, you never get that break, it’s 24/7.”

“Sleep is the key thing, would it be easier to put me in a hotel and keep the child in the familiar home with all the necessary equipment”

“Allowed to sleep like a normal person”

“So when you’re not so mentally exhausted, it makes you a better parent”

“Me and my partner are having relationship issues due to not being able to function as a family would. It’s sad there isn’t anything after diagnosis. It really does affect every day living”

“It’s too complex. You have to fight and fight for every single little thing. And that’s so wrong”

“When you go for an appointment they say ‘do you work?’ and you say yeah and you get a ‘hmmm’. And that’s all you get.”

“A lot of parents say that the best information they get is from each other, other parents”

“[anon] is two on one the whole times, across the board, his risk assessments, the lot. [...my husband] goes to work and although he’s two at all times, it’s only me looking after all three of them”

“I think what needs to be looked at across the board is this kind of speculate to accumulate. If they put the money in and give us support now, it’s not going to impact on the health service and mental health”

“You’re going to end up [...] if it carries on, you’re going to end up with a lot of kids in care”



# Conclusion

## Existing Service

Based on the feedback from parent's and carers through the questionnaire and focus groups;

- Currently the most accessed types of short break are sporting and leisure activities, and social activities with other young people. Activities in the school holidays and respite / overnight are the most accessed. The least accessed types of service are those that support independence, educational activities and those providing support in the home. Short breaks services requiring a referral are the most accessed, personal support breaks and breaks in a mainstream setting are the next most accessed, breaks in the community (i.e. not requiring a referral) are the least accessed. The majority of negative comments relate to the organisation of short breaks rather than the breaks or services themselves.
- 38% of respondents do not access short breaks services. Almost half the children not accessing short breaks services are under 11 (47.6% of under 5s, 47.6% 5-11). 22.8% of children attending a special school do not access short breaks services, of those attending mainstream schools nearly double (45%) do not access short breaks services. The major factor leading to this is lack of knowledge, information or awareness of the services from parents, carers and professionals. There is a misconception that short breaks services relate to holidays or getaways; there is also a lack of signposting from related agencies, this is discussed further in the barriers to service section.
- Although parents and carers felt short breaks services met the needs of 61% of children accessing them, about half the adults accessing the services feel that they do not meet their needs. The two main reasons for this are; not enough time or support i.e. more access is required; the second is the organisation of the breaks, i.e. the travel time means the parent or carer does not get a break, or the parent or carer has a number of children with SEND who do not all attend the break at the same time meaning the parent does not get a break.
- Families of children with SEND experience inequity of service, some seem to receive a good level of support whereas some receive nothing; this is best demonstrated with the focus group activity, where people stated "they got" and "would like" the same thing for the service. Looking at the questionnaire data there is not one group that is most affected any more or less than another; the inequity is experienced equally as there no one group in particular that that is overlooked; this suggests an issue with the administration of short breaks, and the reach and availability information about short breaks .

## Barriers to Service

- From what respondents and participants have fed back, the biggest barrier to service is lack of information; about what is available and how to access. This includes the lack of information from associated services and professionals.

- The way the current system is set up seems to be hindering some people from accessing some provision, as at times the child and family or carers needs to be referred and assessed. Parent and carer feedback suggests that this can be a long complex process, with the responsibility of “making the case” and the referral apparently resting on an individual. The process is not seen as transparent and there is a feeling that if a family has a ‘good’ social worker they receive better support and better access, than others.

## Service Developments

- Two thirds of service users taking part in this engagement feel that existing provision does not meet their needs, it is clear that some form of short break improvement needs to be undertaken. When participants are asked about the service they would like, responses including “anything” and “anytime” confirm an unmet need. 38% of people completing the questionnaire do not access the provision also strengthens the case for changes to the way short breaks services are delivered; based on the comments from the questionnaires and focus groups the changes to service need to be in the context of the other SEND services, VCSE services and community groups or projects. The support that short breaks services provide families could reduce the burden of other services, particularly social care, health services, and mental health services; services remaining as they are will not address these needs.
- It is overwhelming clear that short breaks services need to review and improve the information about the services that are available, in particular; the eligibility criteria, the process of assessment and decision making, and referral mechanisms. Promotion of existing services needs to be reviewed and improved, the promotion needs to be tailored to the following stakeholder groups; parents and carers and children i.e. potential service users, other SEND professionals and support staff, and associated organisations or services. The information and communication channels for potential service users should be sensitive to the needs of this community and be informed by an equality impact assessment. The communication to professionals and related services or organisations should be clear about eligibility criteria and routes to access services, or signposting to support services.
- Although it is clear that improvements to service need to be made, exactly what needs to be improved is not as clear. All negative comments related to the process of accessing of short breaks services rather than the breaks or activities themselves; it seems that if a parent or carer knows about services and uses services they are happy with the break they receive, even though they may require more hours or support. Based on the comments of parents and carers, how people access short breaks needs to be reviewed and improved. There is a feeling that the assessment and referral process is difficult, not transparent, and that whether someone receives an assessment or referral is dependent upon the social worker allocated to the family. Although participants and respondents did highlight a need for more hours and more support it is unclear whether this is because there is not enough capacity in the system or if the referral process means that people do not receive what is required. The only area where it is clear that capacity should be increased is in the school holidays. How people are assessed and referred into short breaks services should be reviewed, and improved as a priority.

- Participants requested that the service needs to provide;
  - Time to:
    - Rest
    - Do household chores
    - Spend with their other children
    - Spend with their partner
    - Themselves
    - Time to socialise
  - Assurance that the service is safe and staff are properly trained and supported.
  - Engaging, supportive, caring staff
  - Social opportunities for interaction for children and young people
  - Opportunities or support to access mainstream activities, groups, or services
  - Support independent in children and young people
  - New experiences for the children and young people

Based on the findings of this engagement there seems to be a change in preference from care or support at home.

- Community provision should be explored; from what parents and carers have raised, the current provision requires a seemingly lengthy assessment and referral process that is managed by an individual. Currently community provision is underutilised; the assessment and referral process could be considerably reduced or eliminated, by developing community provision with a self-referral system. This could provide short breaks offering social, leisure or sporting activities. Parents would need to be assured that the community group had undergone the appropriate checks and were “safe” and “properly trained”. This engagement only explored financial contribution, which the majority of parents would consider; contributing in other ways should be explored further.
- Almost half the people completing the questionnaire expressed an interest in being involved in giving feedback in the future. This high level of interest should be harnessed in the development of SEND services. It is recommended that a co-production approach should continue to be adopted to develop services, this should not be limited to one group, but utilise a number of different ways of giving views; targeting particular demographics of people with particular needs to ensure that the development of services, particularly more specialist services, are informed by those who are most likely to use them. Due to the time sensitive aspect of this particular stakeholder group, meetings or face to face sessions should ideally be kept to a minimum and follow a task and finish structure with very clear purpose. Due to the feeling of a “lack of understanding” it is recommended that Client / Patient stories be used to illustrate need or situation, particularly with partner agencies and professionals, when developing, or changing services. As services develop a client experience programme should be employed, ensuring that the service requirements highlighted from this engagement work are being met; this should be run at regular intervals to ensure the service is improving as required.

## Recommendations

Based on the information gained from this engagement work, the following recommendations are to be taken forward by the Short Breaks Steering Group:

1. Short breaks provision requires improvement to expand reach and improve support.
2. There are three areas that require review and improvement as a priority;
  - i. Information relating to short breaks provision for parents, carers and professionals.
  - ii. The assessment and referral process and eligibility criteria for short break provision
  - iii. The capacity of short break activities in the school holidays.
3. Existing short breaks services, and those being introduced or developed should meet the requirements of parents and carers, that have been highlighted during this engagement exercise. The list of requirements can be seen on [page 27](#).
4. The provision of short breaks by communities is low; this area of provision should be explored. Parent and carer contribution to services should also be explored further.
5. A clear plan for gathering experiences and views about short breaks services needs to be developed. This is based on the very high number of participants expressing an interest in giving their views and being involved in the development of service in the future. A number of ways for people accessing services to give their views and experiences should be developed.
6. This engagement only looked at the views of parents and carers, any service developments or changes should have a robust equality impact assessment to ensure that all groups are involved in ways that are appropriate for them. Particular attention should be focussed on; Children and Young People with SEND, and people from Black Minority Ethnic (BME) backgrounds and communities.



