

**Children, Young People's and Families  
Sheffield City Council**

**Sheffield Short Breaks for Parent/carers of Disabled  
Children and Young People - Review**

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**Findings of Conversations  
April 2014 to March 2015**

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## **1. Introduction**

This report presents the findings of the conversations on the Sheffield Short Break Services for disabled children that took place between April 2014 and March 2015.

## **2. Background**

In 2007 central government launched the 'Aiming High for Disabled Children' programme which aimed to improve services, including short breaks provision.

Several consultation events took place to inform this new transformation programme, and this informed the expansion of the services at the time. Since this time there has not been a citywide review of the offer to families.

Between April and March 2015, Sheffield City Council, Sheffield Clinical Commissioning Group and the Sheffield Children's NHS Foundation Trust worked in partnership to hold conversations with parent/carers, staff groups and providers on the short break services in Sheffield, and commissioned activities to hear the views of disabled children.

## **3. Purpose of the Conversations**

The purpose of the initial conversations was to reach as many people as possible and hold general discussions to inform the thinking about future delivery. This would in turn help identify what further analysis was required, and contribute to informing the process for a consultation on the options.

## **4. Themes**

The conversations highlighted a number of themes which applied across most or, in some cases, all of the services. As such the findings are presented within the context of these themes. These are:

- The impact of caring for a disabled child
- The range and benefits of short break and respite services in Sheffield
- Information and processes
- Developing and accessing inclusive mainstream services
- Flexibility
- Trust in staff, skills, capabilities and settings
- Transition and services 16 to 25
- Increased focus on outcomes and life skills
- Equity of access
- Child care

Due to the nature of the open-ended questions there was a wide range of discussion, and there were many common themes as well as variations in what parent/carers told us. The results are set out in common themes, with specific service areas considered where relevant. The methodology is explained in Appendix 1.

Throughout the document, direct quotes from the consultation will be displayed in blue boxes.

## **5. The Findings**

### **5.1 The impact of caring for a disabled child**

Caring for a disabled child can have a significant impact on the health and wellbeing of parent/carers and their other children, as well as on the life of the disabled child themselves. Some parent/carers reported that they need to develop significant knowledge about their child, spending large amounts of time researching their child's needs. The need to be ready and able to liaise with many different professionals appeared to put added pressure on the parent/carers. One parent/carer suggested the family as a whole unit is overlooked.

"I have had to become very knowledgeable ... I spend my nights on the internet researching everything..."

"There needs to be more understanding of what we all as parents have to go through on a day to day basis, it's hard work".

"...it is important to see, look at the support for the whole family; it is not just about the disabled child".

Several parent/carers reported that 'sleep disturbance' and 'challenging behaviour' has a notable impact on the lives of the whole family.

Challenging behaviour can make daily activities for a family, such as going shopping, for a walk, or a bite to eat, extremely difficult. It can also make using mainstream leisure services, such as swimming sessions or sports clubs, difficult. It impacts on parents when caring, and on the social lives and education of siblings. There was a lot of interest in the pilot workshops that had been run to help enhance parent/carer's skills in managing challenging behaviour, and requests for these to be more widely available.

“...it’s really difficult going to general places, to see a film or swimming ... everyone stares at you as if you’re a bad parent... sometimes it’s just not worth it...”

“Swimming is particularly bad, the changing rooms are small, the other children so noisy he can’t cope...”

“...how can my daughter ever have friends home when her brother can get so aggressive and hit out ...”

The impact of sleep disturbance was also reported as wide ranging; impacting on parent/carers’ ability to function, ability to work, and on their physical and mental health. It can also have an impact on siblings’ ability to study and maintain friendships. A small number of parent/carers reported using either day care short breaks or respite provision as an opportunity to catch up on lost sleep.

“...sometimes it’s hard for us to keep functioning, just to keep going ... Respite is critical in helping us get a full uninterrupted night’s sleep ...”

“...it’s the only chance we have to have a good night’s sleep, and our other children...it’s the only time they get some sleep, it affects them too...”

“... it’s difficult for his brother to do his homework, then he’s sleepy too the next day when he’s at school...”

Many parent/carers felt that short break services help by providing a much needed break from caring and a time for the family to do things together. For some families a short break allows them the time to access other types of support.

A number of parent/carers spoke highly of specific services and of daytime and overnight staff groups. They highlighted that many staff will offer support wider than their general role, extending to outreach support and providing information and advice which can help at home.

The Multi Agency Support Team (MAST) approach was discussed as a service that works well. There were requests for more expertise of this type.

### **What we are doing:**

- The council are working with partners to identify and implement ways to improve support for families in Sheffield on Sleep and Behaviour difficulties, within our available resources
- The council is training a number of staff to offer support on sleep issues
- We have looked around the country for examples of good practice on Sleep and Behaviour Management
- We commissioned some Supporting Positive Behaviour workshops for family carers

## **5.2 The range and benefits of the short break and respite services in Sheffield**

Many parent/carers and staff felt that overall there is a good variety of provision available across the city. For some families it seemed to work well and staff seemed confident that families were happy with their services. However, some staff also felt that parent/carers do not necessarily know the full range of choices available. Some staff felt they didn't have sufficient knowledge and understanding of all services to discuss with families the options available to them. This appeared to be one of the main challenges in supporting families to make informed choices.

A number of staff highlighted the challenges of supporting children with increasingly complex health needs and challenging behaviour. Where settings have a predominantly high level of children with complex needs, significant pressure is placed on them to continue to provide a good service. Difficulties in placing children with the most complex needs were reported across almost all areas of service from daytime to overnight care.

There was some discussion on wider issues, such as the changes in benefits and welfare, which are viewed as having an increasing impact on families need for a short break.

"It works well, let's not change it..."

"I think Sheffield is good, there is a much broader range of services here, and more early support...I don't think families realise how much there is here..."

"I didn't even know what was out there... how did you all find out?"

"I don't feel confident to advise my parents...I was so surprised to see all the options available." - Member of staff

### 5.2.1 Short Break Grant

There was a resounding message that parent/carers value the short break grant. They like the straightforward application process, the lack of bureaucracy and the control and flexibility that it offers.

The grant enables parent/carers to access much broader types of short break activities which can better meet the diverse needs and circumstances of their child and family situation, it enables a short break to be tailor-made to their needs. Several parent/carers felt it was the only way that they could afford a holiday. It was also seen to be of benefit to siblings.

“It is wonderful provision...very straightforward... administered quickly and easily...”

“The flexibility ... is brilliant ...used to access a great deal of activities for us all as a family ... and an overnight stay for myself and my husband...”

“We do so much with it...it is amazing how far we can make the grant go.”

“My son ... can go to general settings, without people realising he has a disability...”

“Families’ needs are all so very different, it would be impossible for commissioners to commission services to meet every need; the short break grant lets families do this themselves .....”

For many parent/carers a short break grant is the only short break provision that they use. From the conversations, this was for a variety of reasons, including;

- Children not being able to cope well within group settings
- Not wanting to leave a child that needs personal care
- Not wanting a short break that means being away from their child

Many parent/carers expressed significant concern about the possibility that the grant programme could stop running. On the other hand, some, who received a short break grant and other short break services, reported they would prefer to give up the grant to keep their other services, or have a reduced grant payment, and one parent was happy to take fewer hours.

Parent/carers also suggested more robust procedures - such as increased monitoring of the use of the grant and spend - were introduced. Parent/carers raised means-testing, although this was met with mixed views.

“It is the only thing we have ... my daughter cannot cope with groups or clubs ... this is all we have...please don't take it away.”

“I would be happy to give up the grant if it means keeping overnight...”

“The forms should be made harder and require more evidence.”

Overwhelmingly, parent/carers suggested that the short break grant should always be available for the summer holiday. A small number felt the grant should be applicable for each disabled children, rather than one grant per family and some parent/carers felt that having to spend the grant by the 31<sup>st</sup> March each year was sometimes restrictive.

#### **What we are doing:**

- We are reviewing elements of the short break grant programme for future delivery
- We are learning from how families use the grant, and the messages that have come from these conversations

#### **5.2.2 Daytime short breaks in: a) mainstream clubs with non-disabled children and b) in targeted clubs for disabled children only**

On the whole parent/carers spoke very highly of the targeted daytime clubs. Many of them gave examples of what they described as excellent delivery. Children also showed that they enjoyed their time and the activities at the clubs.

Elements of all daytime clubs that were very important to parent/carers were:

- Being able to trust staff and know that they would care for the children
- Clubs that are proactively welcoming to disabled children
- A positively proactive ‘can do’ attitude, where barriers to doing things are overcome
- Good staff skills
- Children being familiar with both staff and setting, which enabled children to settle and engage with the club better
- Safety of the building
- Age appropriate and ‘age ability’ appropriate activities
- The availability of a number of different rooms for various activities

However, it was raised that there is a need to develop or build upon specific areas of provision. The areas where parent/carers and staff felt that there were still difficulties in finding and accessing daytime short breaks included:

- Children with very high complex needs, in particular challenging behaviour – parent/carers have less choice and may have to travel further
- Children with specialist health problems or physical disabilities
- Age appropriate provision for young people aged 18 and over (*see also Transition*)
- Provision for children under 8 years old
- Children in the north of the City
- Options for where intensive interventions are needed, particularly where children may not be engaging with services
- Short breaks based at Special Schools - children’s familiarity with the setting would help them to participate and school-based provision would be supportive for parents

Parent/carers clearly valued the daytime short break opportunities, as a benefit to them as well as their children. Children attending a mainstream club with additional support for their short break worked for some families but not all, particularly not for children with complex needs.

“...most of the clubs are aimed at children with learning difficulties and there is not much for my son...” - mother of a wheelchair-bound young boy.

“I need to know they [the staff] are not going to call me ... I can do things with my other children ...”

“My son is 19 now... I went to have a look [at a daytime centre] when he was 18, but I wouldn’t, I couldn’t leave him there...everyone else was 50 ...he would have sat in the corner.”

“Inclusion a good idea but it does not work for all children... even with support my son sat in the corner... he could not cope with the environment, too busy, too much noise...”

Suggestions to support sustainability of the services included: families making a payment for the clubs; paying for specific activities; having fewer sessions; and a more robust assessment of who receives short break services so they go to families who need them.

Some parent/carers suggested ideas for different types of activities, such as family fun days, events and coffee mornings, where parent/carers and children could come together. A small number suggested the possibility of parent-run sessions, and fundraising to fund the events.

#### **What we are doing:**

- We commissioned training for the Special Needs Inclusion Play Service (SNIPs) to offer training to both targeted and mainstream clubs on positive behaviour approaches
- We are reviewing our daytime short break provision across the City and will commission to work towards equitable access, in terms of geography and need

### **5.2.3 Direct Payments and Personal Assistants**

There were very mixed views about Direct Payments. The majority of parent/carers who have a Direct Payment use it to employ a Personal Assistant and there were some examples of a Direct Payment working well, once it was in place. Some staff reported the positive and creative use of Direct Payments as providing a good approach for some children who find it difficult to use other services.

The main concerns and challenges were seen as:

- A lack of information about Direct Payments
- Having to take the responsibilities of being an employer
- Managing Direct Payment budgets can be difficult for some families
- A difficulty in finding a Personal Assistant, in particular for children with more complex care needs
- A difficulty of finding enjoyable and worthwhile activities for children to do with their Personal Assistant but at a low cost
- The breakdown in family members acting as Personal Assistants can be difficult for parents
- A need to improve the training of Personal Assistants was suggested.

Some parent/carers who had, and some who had not, tried a Direct Payment expressed a preference for a delivered service.

“...you feel like you’re on your own with a direct payment...but if you use an agency it’s not consistent.”

“I tried it, it didn’t work ... I went through the whole process...but couldn’t find anyone...”

“Well...they just go to Meadowhall and back on the bus...”

#### **What we are doing:**

- A review of the information available to families about Direct Payments is underway, parent/carers will be invited to be involved.

#### **5.2.4 Overnight Respite Care**

Parent/carers valued residential overnight short break provision for a number of key reasons:

- It offers the chance of a night's break
- The consistency and reliability means parent/carers can plan their time
- The consistency is reassuring and essential for some of the children, and enables them to have regular contact and make friends
- The regular and consistent nature of service enabled the home to balance children's ages and needs
- Parent/carers had full trust in the staff, which they felt enabled them to have a proper break
- Staff go beyond the traditional role into offering outreach support and care, which families felt helped them greatly
- The homes offer additional activities both in and out of the setting
- Developing the child's independent life skills
- It is seen by some children as their 'sleepover'

For children, the social side of overnight respite was one of the most important elements. For example, they enjoyed eating and watching television together. Children indicated that they enjoyed a range of different activities offered, including; gardening; listening to music; trips out; making craft items; and many more. They were proud of their residential home and the facilities there, and particularly proud of their bedrooms.

Parents saw the limitations of overnight respite care as including:

- A lack of flexibility to enable parent/carers to take advantage of occasional evenings out with family or friends
- No emergency beds for rare situations such as funerals or if a parent was sick
- Inequity in access between educational and social care residential homes

Families and staff spoke about how the homes will sometimes offer additional nights to a family when they have availability and also of how some parent/carers will swap nights between themselves. As the balance of care needs and the dynamics of the group of children needs to be considered, staff reported this can lead to difficulty or may appear that one family is accessing more support than another.

“It lets me have a full uninterrupted night’s sleep ... it’s the only chance I get”

“It’s a lifeline...and we can spend time together and as a family”

“He loves it ... it’s his sleepover ...”

“She [member of staff] called me up...she knew I had been ill...she called to see how I was and if there was anything they could do...they offer so much more...I can’t tell you how helpful it is”.

One major concern was the lack of what parent/carers described as appropriate overnight provision for young people once they reached 18 (see also Transition).

Health staff felt that there was an increase in children with complex health needs wanting respite in the family home - rather than in a health setting. Social care also reported some parents wanted their children to remain in their own house for care.

There were positive discussions about joint health and social care services, joint assessments, budgets and communication.

Finding suitable overnight foster families for children with complex needs is also difficult. A small number of parent/carers said that they would consider foster care overnight services while others preferred residential care. This was because they felt that the residential home offered more social activities, a lesser risk of breakdown in placement, less likely to have the short break cancelled due to illness and a larger physical space for children with complex needs.

There were suggestions to explore the adult services Family Placement Model, joint health and social care provision, and joint databases.

**What we are doing:**

- We are working closely with adult services to explore opportunities for young people aged 18 and over
- We have begun to explore further what young people want when they reach 18
- We have developed a recruitment campaign to increase our number of foster carers

### 5.3 Information and processes

Information and processes for accessing short break and respite services emerged as a key issue across all service elements.

Generally parent/carers felt that there was insufficient information and guidance available across daytime and overnight short breaks on:

- The range of services available
- How to access services
- Eligibility criteria
- The process for allocating the amount of short break or respite care offered

The suggestions for better processes and information were specific to the type of services:

- While many parent/carers found the short break grant process straightforward some were confused about what it could be spent on, thinking it had to be used as for a 'break away'. Several parents liked the idea of changing the name to an Inclusion Grant.
- A number of parent/carers spoke highly of the Special Needs Inclusive Playcare Service (SNIPs) visits, assessment process and the support for children to engage in daytime clubs, whilst others were unsure of the role of the service. Specifically parent/carers wanted improved information on what individual clubs offered; their skills and the level / types of difficulty they could support.
- There was an overwhelming consensus from the parent/carers who responded that the Direct Payment process and assessment could be improved. Parent/carers saw it as long and difficult with insufficient information on the practical and legal elements, such as how to become an employer and tax issues.
- Some parents felt there was insufficient information about the process for overnight respite allocation in general.
- A small number asked for improved transparency on how the Helena Specialist Nursing Team support packages were determined and also highlighted the stress of the process, and travelling to medical appointments, for them and their child.
- In general, it was felt that we needed improved working between agencies
- Better information on disabled specific opportunities in mainstream settings is also needed. Parents gave the Ice Bumper Cars at Ice Sheffield as an example.

There were suggestions for a One-Stop Shop of information and a Trip Advisor type of website where parent/carers could share experiences and good services, and a generally improved Local Offer. Non-social media suggestions included: e-mail newsletters; information in welcome packs from school; information from services; and phone apps.

Some parent/carers felt passed around when trying to access support. They felt that this affected the continuity of care for their child. They also spoke of a feeling of having to fight for services.

Staff suggested that while they work well in their own services, improving the links and joint working between social care and health, across children's and adults, and across other children's services, would lead to better understanding of the packages of care for children.

Parent/carers questioned the process of assessing a child's need for short breaks services, including the Short Break Grant. They suggested a stronger and more robust process to ensure that children with the greatest and most complex needs receive the services.

"I heard about things from other parents rather than through the official channel."

"There had been inconsistent messages and advice [about DP's] ... more information should be in writing."

"I didn't know about all these short break options, until I saw the presentation, there's more than I thought ..." (staff member)

"They [SNIPS] were great; staff visited and discussed with us what we wanted, listened to my son about what he likes doing ... and they contacted me after the service had begun to see how it was going".

"There are too many hoops to jump through; it kind of defeats the object of respite and support."

"... Do all families really need [the service], their needs are lower, what about children with more complex need?"

**What we are doing:**

- We have revised Short Breaks Grant information, and are updating general information on short break services.

**5.4 Developing and accessing inclusive mainstream services**

Many parent/carers were interested in accessing mainstream leisure services as a family, and there were some good experiences shared such as, inclusive mainstream nurseries, some Activity Sheffield clubs and a swimming session provider. However, there were also

consistent challenges that parent/carers experienced, which varied depending upon whether the child had physical or learning difficulty.

Challenging behaviour was seen as a major barrier to accessing mainstream provision as a family, with parent/carers feeling that they and their child(ren) were being judged by other people.

High levels of noise, large numbers of other children and other children's boisterous behaviour were cited as often causing distress and anxiety for their disabled child(ren). Public swimming sessions were raised as being particularly difficult as they usually have small changing rooms and often other children running about.

A number of parent/carers reported that sometimes their place would be cancelled as they were not attending regularly. Parent/ carers felt that, for children who have fluctuating conditions and/or emotional behavioural difficulties, regular attendance can be difficult.

The difficulty of using universal leisure services such as parks was highlighted by one mother, whose 19 year old daughter loved to go on the swings. During the day she could be intimidating to younger children, in the evening she was intimidated by young people.

One mother with a son with profound physical disabilities found a lack of understanding about what accessibility really meant, and suggested providers sometimes 'tick the box' but do not provide real accessibility.

It is clearly difficult for some mainstream services to meet the needs of a child that may, for example, need 1:1 personal care needs, without additional support. While parent/carers could stay and support their child, they felt that this was inappropriate for older children who need to develop more independence. Several also felt that there was a lack of training around children's medical needs in universal services.

Parent/carers suggested quiet or disabled only swimming sessions; specialist playground sessions; Scouts, Guides, Cubs and Brownies, offering specialist clubs for children with disabilities (perhaps located in Special Schools); and more family fun days.

Staff felt that the Special Needs Inclusion Play Service (SNIPs) working in geographical areas was improving the knowledge of not only short break providers but also mainstream clubs to meet the needs of disabled children.

“I’m embarrassed...other parents turn round and stare at you, they think you are a bad parent, you can’t relax.”

“When I go to the park, I see all these Boden style mothers with their perfect children and it sends me into emotional turmoil...my child still needs personal care ...”

“Some places don’t know what accessibility really means to parents ...places say they have wheelchair access, but are the paths gravelly ...and long queues...”

“Inclusion is a good idea but it does not work for all children, my son sat in the corner, he could not take all the noise...”

#### **What we are doing:**

- We support mainstream clubs where disabled children attend for their short break, with guidance, advice and sometimes training
- We are looking at how we can do more of this going forward.

### **5.5 Flexibility**

Flexibility was of significant interest and a recurring theme for many parent/carers, and as such has been identified as a specific issue. Some parent/carers asked if there could be more flexibility with Saturday and Holiday clubs, such as being able to book directly with providers themselves, arranging different days during school holidays, and ‘banking’ days if they could not attend.

Parent/carers also felt the set allocation for overnight respite and the lack of flexibility to change nights had an impact on their opportunities to have a life outside of caring. However, for daytime and overnight services families recognised that this was difficult in practice, particularly for children with more complex needs, and felt the match of the children attending was most important overall.

In comparison, one of the main benefits parent/carers reported for the short breaks grant was the flexibility to use the grant however families felt best.

In terms of overall packages of care, and specifically where a child may access more than one short break or respite service, both parent/carers and staff highlighted the need to improve processes and flexibility where a service is not meeting a child’s needs or the needs have changed. At these times staff felt that the tendency is to layer additional services on top of an initial service, which can have an adverse impact. More flexible approaches to the

packages of service were suggested, that place the child and their outcomes at the centre of the process, and removing the rigidity of a set package of the number of hours or nights.

The Person Centred Planning approach was seen as a positive approach.

“..work has a really good Christmas ‘Do’, but we never go as it never falls on a respite night...it’s really disappointing”

“...we rarely go out together”

“..Flexibility is not going to be easy for the services and getting the right match is the most important thing overall.”

### **5.6 Trust in staff, skills, capabilities and settings**

It was clear from parent/carers that they felt that a short break is only a genuine short break when they have trust and confidence in the service provider, the staff group, or Personal Assistant. These were important issues for parent/carers who had children accessing daytime short break clubs or using a personal assistant or 1:1 support. However, it was overwhelmingly so for parents who had children accessing short break overnight services.

Parent/carers particularly valued:

- Daytime short break and overnight residential staff expertise; having confidence that the staff know their child(ren) well, can communicate with and support them and, are able to manage their behaviours
- Knowing they would not be called out during the night or having to worry about damage to the homes and associated costs
- Good staff-child relationships and how this builds the children’s confidence
- Very proactively welcoming staff who support the children’s engagement in a range of activities
- Staff listening to children and young people voices, wishes and feelings, and helping them influence service delivery
- Staff felt that daytime and overnight services have good relationships with families, particularly those in greatest need, often offering the families additional support beyond the short break or respite care.

“It’s the trust in the staff, that’s what gives us a break, we can relax because we trust them to look after him, we know we won’t get called in the middle of the night.”

“Staff were key to the enjoyment of the children in residential homes they gave them space they needed to be alone but also sat with them when they wanted company or felt they wanted to join in ...staff really helped to promote the teamwork side of life ...” – report from involvement of children and young people

“... they knew we were going through a tough time, and they called to check I was ok and to see if there was anything else they could do to help us ...they offer more than just respite care” - parent of child using residential short break

“...clubs proactively welcoming children with disabilities, that’s the most important thing, that they believe in them, it’s not just a job...there are no barriers to them doing anything.”

Visits to the homes highlighted that staff were ‘key’ to the children’s enjoyment; staff were knowledgeable, attentive to needs, particularly for those with alternative methods of communication.

In contrast, finding 1:1 support workers or a personal assistant with the right skills for a child with high level complex care, medical needs, or non-verbal communication, can be difficult. There was a sense among staff that there was still a place for enhancing skills, and consistency in competences. It was generally felt that we could improve goal-setting and outcomes for individual children. Linking with Educational, Health and Care Plans (EHC plans) was seen by staff as a positive step.

There was also general agreement that mainstream services offering day care short breaks with additional support would benefit from further training and skills development. This was felt of particular importance in relation to understanding children with Autistic Spectrum Disorder (ASD). Developing workforce training with parent/carers and including parent/carers in delivering training was also suggested.

**What we are doing:**

- We will ensure in our contracts for services that their standards reflect parent/carers views on trust, capabilities and skills

## 5.7 Transition and services 16 to 25

Transition issues can relate to a move between services, between clubs, from early years, and from children's services to adult's services.

Transitioning from children's to adult's services was raised as a significant concern for a number of parent/carers:

- For those who had experienced transition, or it was in the near future, there was an overwhelming view that planning transition from children's to adult's services, whether from health or social care, needed to begin earlier
- Parent/carers reported finding the process 'really hard' for themselves, and generating anxiety and distress in their children. This seemed to be compounded by the feeling that the transition was sometimes into 'nothing'
- Parent/carers reported finding the daytime short breaks not always age or ability appropriate, and having too wide an age range
- Overnight provision for young people aged 18 and over was a major worry for parent/carers, compounded by a concern about how much services would cost
- A general move into adult's and personalisation or direct payment systems was felt to be confusing with a lack of clarity about the points system.

Staff felt that the transition from children's services into adult's services has improved. However, it was also recognised that pressures on capacity were leading to delays in the provision of services. There was also discussion about whether children's and adult's services use the same eligibility criteria. Staff reported that some families are very concerned and anxious about their child's transition into adult's services.

Parents were very pleased to hear about the Education, Health and Care (EHC) Plans spanning the whole age range of 0 – 25 year olds. Parent/carers welcomed the change and felt the consistency would be good for the child. For some people, this was new information.

Transition was also raised with respect to younger children, those under 8, and moving into day care or overnight care provision.

“It’s a battle... it can be extreme and frightening and for some young people, too much to cope with”

“My child sometimes needs activities associated with younger children, simple motor skills, even play dough or Lego, and then being offered adult provision with 40 or 50 year olds is very frightening”

“We visited the day care provision...we just could not let our son go...”.

“...does this mean children’s services will be delivering for up to 25 year olds instead of adult’s? can clubs have the funding to run up to 25?”

“...will my child be able to access the Sheffield Children’s Hospital up to 25?”

“It took us ages to find a place and he stayed in nursery longer...” - parent/carer of a child under 8.

#### **What we are doing:**

- We have committed to work closely with Communities (Adult Services) on improving the progression of young people into services post 18
- We are developing joint visions for the future and long term joint plans

#### **5.8 Increased focus upon outcomes and life skills**

Many parents talked about the benefits of children attending daytime short break and overnight services, such as making friends, learning how to socialise with other children, and eating together. Parent/carers particularly praised daytime clubs which undertook activities which promoted confidence, self-esteem, and life skills such as using public transport and handling money. Some saw an improvement in their child’s behaviour, social skills, eating, and/or communication through attending Saturday and Holiday Clubs, and reported a positive impact which often translated into the family home. Daytime and overnight short break provision which had an additional benefit was something parents wanted to increase.

Parent/carers asked for:

- More activities based outdoors, and activities which would promote physical wellbeing and confidence
- ‘Safe but risk taking’ activities, which parent/carers might feel less confident to do
- Outcomes-based approaches, in particular using money, using public transport, shopping and cooking

The Short Breaks Grant was also seen positively by parent/carers in how it enabled their children to access 'cool' or physical activities which helped develop their skills, such as swimming, climbing, snorkelling, or chess.

"I daren't take her out on a bike...but she'd love it..."

"He spends too much time in his bedroom on the computer, I want him to get involved in physical activities, try things out..."

"I think it would be great for our children to be getting to know the real world"

"Things that I don't have the confidence to do with him, I'd be too protective ... but I know he could do... and it would improve his confidence..."

"...life skills which would help young people move into independence and independent living".

#### **What we are doing:**

- We are including more outcomes and life skills into our daytime service contracts and will set these as a priority

## **5.9 Equity**

Equity of access to short breaks is important across all demographics, such as: heritage culture and religion; age; gender; disability or need; geographical area, etc.

In terms of information and communication, an interpreter was commissioned for one parent/carer attending a Town Hall event. The parent/carer had experienced a lack of information in suitable formats for non-English speaking families.

One BME parent/carer, who works in a related field, was confident in her view that some families from BME communities were put off accessing short break and respite services for cultural reasons - due to the terminology of 'Short Break'. The term 'break' could be seen in some cultures negatively, and parent/carers may not want professionals they do not know caring for their child. A stepped change introduction to the services, or renaming the concept was suggested, developing a better understanding of what families would like and the barriers to access.

A provider of daytime short breaks has reported difficulties for a family from one community who did not wish for their disabled child to attend a short break club with children who were not from their own community.

Whilst the consultation questions did not ask for information specific to particular groups of the population, or of need, the findings also highlight issues relating to provision for children with specific types of disability, age groups - under 8's and over 18's, and geographical areas, and ethnicity.

### **5.10 Child Care**

Two key areas of concern for parent/carers were the availability of information on childcare options, and the availability of appropriate childcare itself;

- Parent/carers felt that there was a lack of information on childcare options, and they felt unsure about who or where to go to for information
- Parent/carers wanted information available in more than one medium.

Some parent/carers thought that afterschool clubs were sometimes lacking in the physical space to meet some children's additional needs. The clubs also have children attending with a wide range of ages and abilities. One parent reported a difficulty in accessing childcare due to the complex needs of her child, another experienced difficulty finding childcare for her twins, whilst another talked about the difficulty of accessing a school environment.

Finding a Personal Assistant, with the necessary and appropriate skills to provide childcare was also seen as a challenge for some parent/carers.

The majority felt that schools were a good or ideal location to run afterschool or holiday clubs, and considered that a cost of £15 was a fair price for a day's childcare.

## **Appendix 1 – Conversation Methodology**

### **Method of delivery**

The initial conversations with parents and carers took place between April and October 2014, and a range of methods were used:

- The conversations were launched with 3 parent/carer open meetings in Sheffield Town Hall in April 2014, with a presentation followed by table discussions in relation to each service area
- For parent/carers who could not attend, or where they wanted to make further comments, an Online Survey was available
- Paper copies of the questionnaire were available in public libraries, through the Sheffield Parent Carer Forum, the Parent Partnership Service, and to download from the SCC Short Breaks Website
- Focus groups were held to enable more detailed discussion of the issues
- Sheffield City Council fund the Sheffield Parent Carer Forum to support consultation and engagement, this includes a large Family Fun day; this event was used to enabled one to one and small group discussions with parent/carers
- Parent/carers were offered the opportunity of a telephone conversation if they were unable to engage in any of the events.

The slides presented at the launch conversations were available on the Short Breaks website and links to the website were made available through the Sheffield Parent Carer Forum and the Parent Partnership Service.

Staff groups across health, social care and education were invited to staff conversations, and the Children's Engagement team were commissioned to work with children and young people to gather their views on their short break services.

### **Promotion of the Conversations**

Several methods were used to inform parents and carers of the events, and support and promote parents involvement:

- Webpage at [www.sheffield.gov.uk/shortbreaks](http://www.sheffield.gov.uk/shortbreaks)
- Parents Assembly Weekly e-Bulletin: 665 members (including 32 schools)
- Parents Assembly Twitterfeed: 639 followers
- Parents Assembly Facebook page: 215 likes
- The Parent Carer Forum website: more than 600 members
- All Special Schools
- Specialist Saturday / Holiday Day Care Short Break Clubs: 15 providers
- E-mails to all families who received a Short Break Grant (where an e-mail address was available): 900 families

- Telephone calls to all parents who access the Social Care Residential Respite homes
- Foster Carers Forum webpage
- The Parent Partnership Service Facebook page
- The Parent Partnership Service support group network
- All services received information about the events and were asked to encourage and support parent/carer involvement, including: Ryegate House, Sheffield Children's NHS FT; Children's Disability Team; the Children's Residential Respite Homes; the Special Needs Inclusion Play Service; and the Foster Care Support service
- Paper copies were delivered to all community libraries
- A telephone helpline was available through the Parent Partnership Team

### **The Structure of the Conversations**

The three events at the Sheffield Town Hall were introduced by Cllr Drayton, elected member for Children, Young People and Families, supported by Jayne Ludlam, Executive Director for Children, Young People and Families and, Simon Morrit, Chief Executive of the Sheffield Children's NHS Foundation Trust.

The presentation offered an overview of current service delivery, budgets, what parent/carers had already said about services, and an overview of the consultation programme.

Parent/carers could join different table conversations relating to the type of service that they used, or wanted to contribute to the discussion, this included:

- Accessing mainstream or universal services
- Childcare for Disabled Children
- Short Breaks Grant
- Saturday / Holiday and After School Day Care Short Breaks
- Direct Payments, Personal Budgets and Personal Assistants
- Health
- Respite care out of home

The table conversation focused upon four general open questions:

1. What works well?
2. What could be better?
3. How it might be done differently?
4. Any ideas for the future?

During the events, parent/carers were also asked if they would like to take part in a focus group to consider the service areas in more detail.

## Events list

- Town Hall Open meetings April 4<sup>th</sup>, 5<sup>th</sup> and 7<sup>th</sup> 2014
- Parent and Carer online Survey: 29<sup>th</sup> April – 28<sup>th</sup> May 2014
- Foster Carers online Survey: 24<sup>th</sup> July – 7<sup>th</sup> August 2014
- Focus Group on Short Breaks Grant - 14<sup>th</sup> July 2014
- Focus Group on Direct Payments and Personal Assistants: 11<sup>th</sup> September 2014
- Focus group on Saturday / Holiday Day Care Short Breaks: 3<sup>rd</sup> September 2014
- Focus Group Overnight Respite: 12<sup>th</sup> September 2014
- Sheffield Parent Carer Forum Family Fun Day event: August 2014

All Staff involved with council or health delivered short breaks received the same presentations as parent/carers and were invited to be involved through similar events:

- Staff – open meeting and discussion session
- Staff - online Survey: 17<sup>th</sup> July – 8<sup>th</sup> September
- Health Staff online Survey: 22 October – 30 October

The Children’s Engagement Team visited and engaged with children using residential overnight short breaks and some daytime short break services.

## Who took part?

In total 108 parent/carers attended the conversations in the Town Hall in April 2014. Each parent/carer could chose to join up to 2 discussion tables. The most popular requests were for The Short Breaks Grant, Overnight Respite Care and Saturday/School Holiday/Afterschool day care breaks. However, parent/carers could choose different discussions on the day. The breakdown of requests is as below:

<b>Discussion group</b>	<b>No. Registered</b>
Short Break Grant	57
Health Short Breaks/Respite care	24
Overnight respite care out of home	44
Developing access to universal services	15
Saturday, school holiday and after school short break clubs	41
Disabled Children’s Childcare	12
Direct payments/personal budgets/PAs	19
<b>Total</b>	<b>212</b>

In addition;

- 43 parent/carers completed the online survey
- 12 parent/carers took part in the Focus group discussions
- 26 parent/carers took part in discussions at the Sheffield Parent/carer Family Fun Day

- Over 30 staff attended the staff discussion groups, and 21 staff completed online surveys
- The children's engagement team worked with children and young people.

**Two additional sessions were offered in January and March 2015**

- Town Hall open session January 17<sup>th</sup> 2015
- The Circle Open session March 17<sup>th</sup> 2015