

Report – Northamptonshire Short Breaks Co-production workshops

Council for Disabled Children Engagement Report Autumn 2021

Context

Currently, the Northamptonshire Children's Trust (The Trust) and the Northamptonshire Clinical Commissioning Group (CCG) jointly commission the Residential Short Breaks Service which is provided by Northamptonshire Healthcare Foundation Trust (NHFT) and the Sleep Service, Sleep Right Northamptonshire, provided by Scope. The Trust separately commissions Non-Residential Short Breaks, provided by Action for Children.

The need for this service should be seen in the context of the population demographics in Northamptonshire. In 2019 there were a total of 134,966 children and young people between the age of 0 and 25. Furthermore, the number of Education, Health and Care plans (EHCP) in Northamptonshire has increased every year since 2016 with a 5% increase between 2019 and 2020 which is below the East Midlands region increase of 9%. 13.4% of school pupils have an EHCP or are receiving special educational support. This points to the need for creating better services that meet the needs of a growing population of children and young people.

These services form an essential part of the support offered to disabled children and young people and their families, enabling them to lead more ordinary lives. The Trust and the CCG recognise the important role they play in ensuring there are sufficient appropriate and accessible short breaks available across Northamptonshire which meet the needs of local families. These short breaks not only provide children and young people with opportunities to socialise and have fun, but they also provide parents and carers with necessary breaks to enable them to continue to provide care. A previous consultation on services conducted between May and July 2020, found that children, young people and their parents and carers want flexible, integrated services provided in places close to home.

Following on from this consultation, The Trust commissioned the Council for Disabled Children (CDC) to undertake further co-production sessions. These sessions took the form of half day workshops with parents, carers, SEND Board, Commissioners, Practitioners and Community Groups and engagement with children and young people to understand what short breaks are needed in Northamptonshire for disabled children and young people and their parents and carers.

Aims and objectives

Through these sessions we were seeking to take a new approach to co-designing and developing a short break's offer which meets the needs of local families within the existing capacity of The Trust. Some of the core aims of the sessions were to:

- Explore the barriers and opportunities for disabled children and young people in their local communities
- Explore the need for different types of short break opportunities including the impact of COVID-19
- Co-produce creative and innovative ideas to improve opportunities for children and young people to be part of their communities; to have positive, enriching and ambitious experiences; and for their families to be supported to continue in their caring role

All activity was underpinned by The Trust's core values which are to:

- Be child focused and work with the whole family
- Make a difference with trust and integrity
- Concentrate on the best solution
- Act with respect, kindness and compassion
- Communicate well
- Do the best job of your life every single day

Methodology

To successfully capture feedback from a variety of professionals and parent carers, we engaged with different audiences through tailored activity. By creating different opportunities, we were able to reach a wider range of participants in ways which enabled meaningful participation. For example, when we were seeking the views of children and young people we went to the spaces they already attended and felt safe in, and ran several interactive activities which enabled them to engage in a way which suited them. For children and young people who communicate non-verbally, we sought to get their views through observations in short break settings and staff feedback. In total, we met with 15 young people across sites in Kettering, Corby and Daventry.

Our core delivery was through two face-to-face workshops with frontline practitioners, commissioners and parent carers. These sessions were run over two days in different parts of the county to enable us to engage with practitioners and families in different parts of the community, with one session delivered in North Northamptonshire and one in West Northamptonshire. The locations were chosen for ease of access to ensure practitioners from all areas of the county were able to attend. These sessions were delivered face-to-face in a COVID safe way to enable more effective conversations between colleagues and parent carers, as well as a chance for networking after 18 months of virtual meetings. In total 21 participants attended these two sessions, with representatives from the local authorities, health, social care, the voluntary sector and short breaks providers.

Although a small number of parent carers were able to attend the two workshops with professionals, it wasn't easy for all parents to attend. Consequently, we developed a supplementary webinar with a linked survey to increase engagement from this group and keep them informed of the conversations we had in the workshops. The webinar and survey links were shared by The Trust directly to parent carers through local provider networks. The survey was open for a short period of time, closing on the 15th October. During this time, the webinar video received 58 views and 14 people responded to the survey of which 13 were parent carers.

Best practice examples from other areas

As part of the co-design and development process for Northamptonshire's new short breaks offer, it has been important to reflect on existing examples of best practice from across the country. It is useful to draw inspiration from other local areas who have faced similar challenges and used innovative thinking to find co-produced local solutions.

West Sussex

One example that was shared was the offer in West Sussex and their corresponding Short Breaks Statement. In this statement they set out 4 clear tiers of support available to children and young people and their families which include:

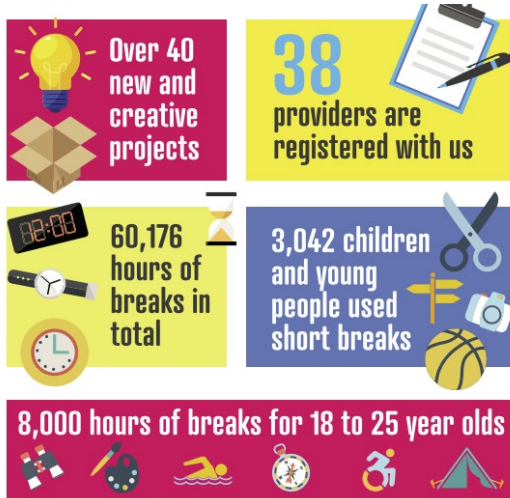
- Community-level support via the Compass Card – the Compass card offers families discounts and opportunities for bespoke, tailored disability sessions at cinemas, leisure centres, cafes, restaurants and other community-based opportunities in the local area
- Opportunities for the whole family to do things together – this tier covers supported short breaks to create different and positive experiences for the family to enjoy time together whilst still having a break from their caring responsibilities through support from a carer or provider
- Universal services – this tier focuses on supporting services in the community to be as inclusive and accessible as possible
- Targeted fun and play – this covers the specialist tier of providers offering short breaks covering socials, arts, sports and leisure activities

West Sussex also provide funds to kickstart innovation pilots to grow activity and develop new short breaks opportunities for children and young people.

The statement itself breaks down information on support available and how to access it in a clear family-friendly way. The experience of families runs through the document with observations from parent carers and children and young people referenced throughout. The document has clear information on the different provisions available, when they take place, details on how to apply and the eligibility criteria in place. Critically, they emphasis in their eligibility criteria that demonstration of 'equivalent need' is accepted in place of proof of diagnoses or benefit payments as part of their needs-led eligibility framework.

In their Short Breaks Statement, they shared some statistics on their delivery from 2019-2020. They stated that Short Breaks were available to children and young people with a wide range of additional needs and/or disabilities including wheelchair users, those with autistic spectrum conditions, profound and multiple learning disabilities and complex health needs.

They also produced a graphic detailing the support they delivered over the year and information on the children and young people who were eligible for this support.



Short Breaks services were delivered for:

- Children and young people under 18 years with additional needs and/or disabilities (up to 25 for some Short Breaks)
- Children and young people who live in West Sussex
- Children and young people who are in receipt of either the middle or high care component of Disability Living Allowance (DLA) or the standard or enhanced rate of Personal Independence Payment (PIP) or have equivalent needs.

London Borough of Bromley

Another example that was shared, was the learning from the recent Short Breaks Provider event that was co-delivered by LB Bromley and the Council for Disabled Children. The event was used to explore opportunities for how short breaks providers can help prepare disabled children and young people for fulfilling adult lives.

Initially the group shared some of their examples of current practices that could be transferred to other areas of delivery, as detailed in the graphic below.



Following on from this, the providers broke down some key areas for development to continue to evolve their delivery, including:

- Think about developing services based on ‘like-minded’ interest and skills rather than age ranges tied to legal or funding arrangements
- Lots of providers are thinking about PFA for young people post-16 how we can extend this down the age range
- It’s important to keep a focus on fun and positive experiences and adapt them to support outcomes
- Create opportunities for providers to work together and think creatively, especially where children and young people are moving from one service to another or accessing more than one provision

These examples were shared in both the face-to-face workshops and in the online survey to encourage participants to consider whether elements of these offers should be incorporated into the future Short Breaks offer in Northamptonshire.

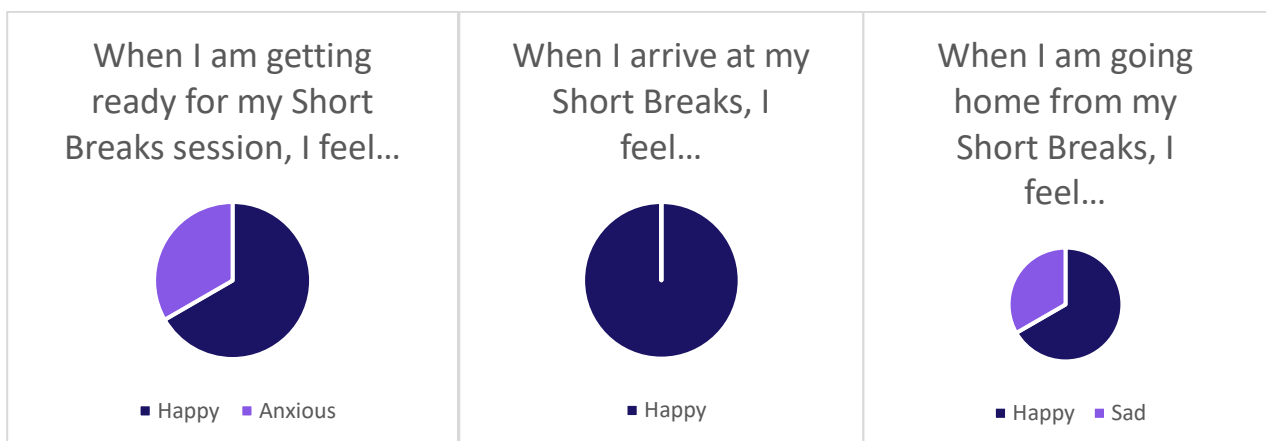
The sessions

Visits to current provisions

In advance of the workshops, webinar and survey, colleagues from The Trust and CDC staff undertook several visits to current providers to get the views, wishes and feelings of disabled children and young people already accessing short breaks services, as well as staff working there. During these visits, staff were able to meet young people at short breaks provisions in Kettering, Corby and Daventry. Additionally, a visit to the residential setting at Northampton was also arranged to meet with staff and see the facilities. During these visits we were able to engage with 4 young people in Kettering, 2 young people in Corby and 9 young people in Daventry.

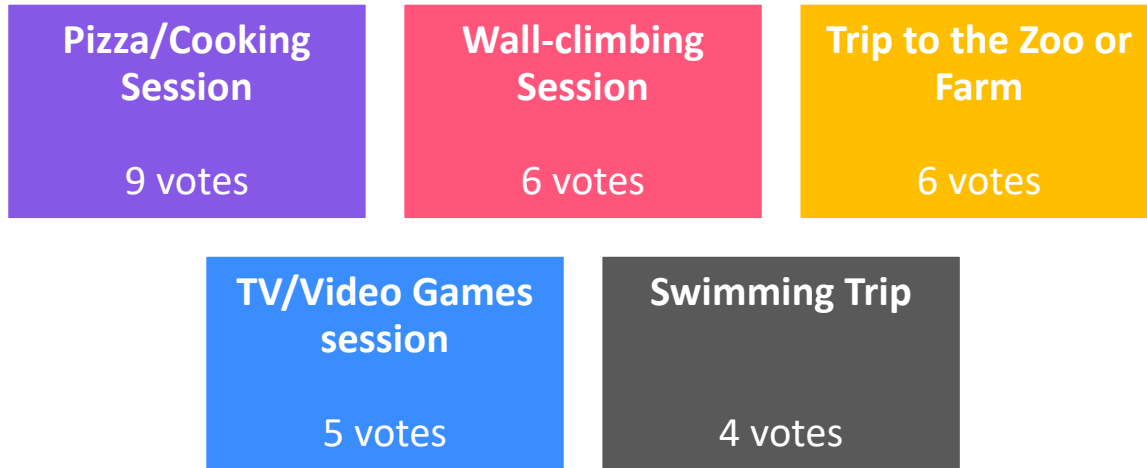
In these sessions we used a variety of different methods to get the young people's feedback including two interactive activities, informal conversations and observations for those who couldn't participate in these activities. It is important to note that the engagement in the different activities varied. 6 young people in Daventry, 3 young people in Kettering and 2 young people in Corby participated in My Perfect Day at Short Breaks but only the 3 young people in Kettering completed the My Feelings worksheet.

The first interactive activity was called My Feelings. To understand how young people feel about their short breaks we asked a series of questions and got the young people to respond by writing down or pointing to a word or colour that represents how this makes them feel. This included how they felt when they were getting ready to go to their Short Breaks and how they felt when they arrived and left. The overwhelming feedback from this activity was that children and young people really enjoyed their experience at short breaks with 100% reporting feeling happy when they arrive at their short breaks. The only negative emotions were the anxiety of getting ready to go and sadness at the point of leaving.

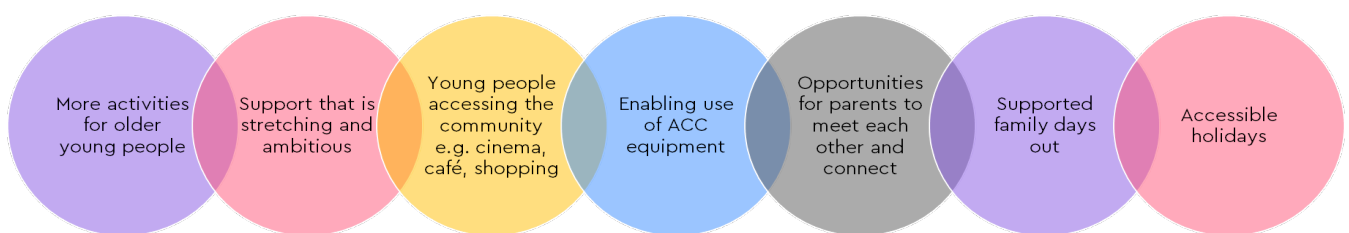


In the second activity, My Perfect Day at Short Breaks, the children and young people picked 5 different activities that would make up their perfect day at short breaks. They were given a prompt sheet with some ideas but also encouraged to come up with any

ideas of their own. There were many different ideas suggested but 5 activities were the most popular. These activities were diverse in nature but all achievable through a short breaks provision.



At one of the settings a carer shared their experiences of the opportunities for older teenagers including what was working well and what could be improved. They discussed the fact that there is a good level of support from the existing short breaks services, and that young people feel happy and safe when they are there, which mirrors the feedback from the My Feelings activity, as well as mentioning that staff know the young people well. However, they also shared some suggestions they had for older young people which should be built into any future designs for short breaks provisions:



Not all young people were able to participate directly in these activities so observations of their experience within Short Breaks were made, with further insight sought from the professionals around them. For example:

- He liked wandering around the outside area, he particularly liked watching all the volunteers doing the gardening, he was laughing a lot when it was lunch time and he was eating his food which he loves

- He loves music and being able to control his own environment. He likes playing football and said he was happy when asked how he feels about being at the club
- He likes routine and seems very happy at the short break, smiling a lot and engaging well with staff. He likes animals and going to the farm.

We were also able to get some feedback from the staff at these provisions on what they thought was most important to consider when redesigning the short breaks offer. 4 key themes emerged out of this conversation:

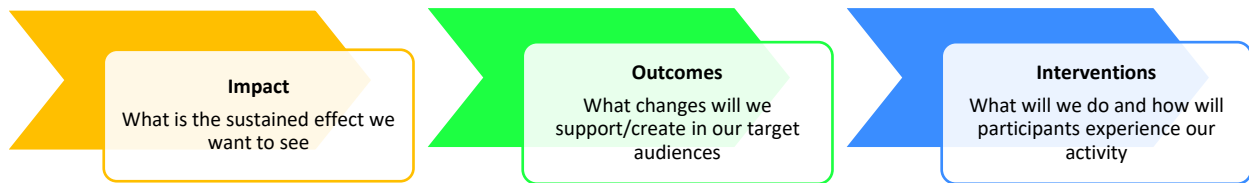
1. **Varied activities** – staff know that the likes of the children vary so much but they have identified that children would really enjoy a theatre group, trampolining, farm trips to see the animals, climbing. All of these tallies with the young people's feedback in My Perfect Day at Short Breaks
2. **Consistency** – staff acknowledge that consistency is important for most children and their parents in terms of routine, venue and staff with regard to building up relationships
3. **Socialisation** – staff have flagged that socialisation is an important part of the activities and learning how to share and consider other children
4. **High quality services** – It is important that the Short Breaks services are of high quality and that parents are confident to leave their children. A way that one setting currently supports parental confidence is by having a handover book to explain what the children have done during the session

Face-to-face workshops

The second stage of this project was the delivery of two face-to-face workshops with practitioners and parent carers to explore in depth and to begin to co-develop a short break's offer which builds on existing services and supports which are working well for families, whilst also creating a space for new and innovative approaches.

The face-to-face sessions included a summary of the legal obligations of the local authority in relation to the provision on short breaks to give a grounding of the legal framework; a review of good practice examples from West Sussex and a London Borough to see what might be possible in Northamptonshire; and the main session focused on co-developing a shared vision. The development was underpinned by the feedback from children, young people, carers and staff at the short breaks providers.

During the second part of the workshop the focus shifted from the current activity onto the longer-term goal/impact we were seeking to achieve so, where necessary, the approaches to short breaks could be redesigned to ensure that they are sufficiently focussed on progress towards the outcomes and ultimately the impact that we seek to achieve for children, young people and families. The diagram below sets out some key questions in defining this approach.

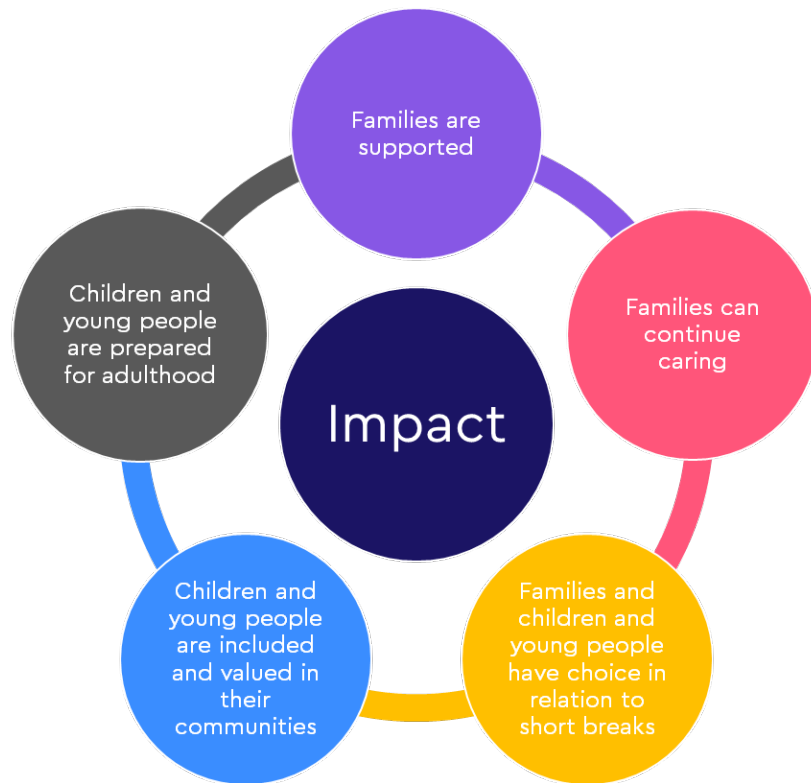


The impact

The first stage was to collectively decide the key impacts we are seeking to achieve with the short breaks provision. Practitioners and parent carers agreed that the focus should be on creating accessible, co-designed opportunities for children and young people which mirror the activities their peers can access. They also recognised that taking a whole-family approach which involves parents, siblings, and the wider family was important.

Linked to some of the feedback from staff at the provisions and the experiences of practitioners in the room, they also emphasised the need for consistent service which young people can understand. Finally, personalised approaches which focus on aspiration building and developing identity were highlighted as a core element of future delivery.

Based on this feedback, 5 key impact statements have been pulled out into the graphic below to be used to guide future planning and delivery of a short breaks offer:



The outcomes

After agreeing these core impact statements, the group moved on to discussing the outcomes they want to achieve for children and young people. There were lots of views shared around this but some of the main areas of feedback were:

- Families to have greater confidence in staff supporting their children and young people and to feel more supported
- Increase capacity in the sector by developing the infrastructure for volunteer and career pathways across the county
- Increase availability of quality support through a well-trained and supported workforce
- Improve matching of staff to maximise their capacities and broaden opportunities for young people
- Increase dynamic ways of working suited to the population by improving information sharing and creating a clear feedback loop

Leading to a series of outcomes as set out below:



Mapping existing supports

The next stage of the session was designed to explore existing interventions and map out the different provisions currently available across the county including considering how well these services meet the needs of the community.

As part of this mapping activity, attendees were asked to consider the barriers that exist, and the steps that need to be taken to ensure the activities align with the impact and outcomes set out above. In this process, participants agreed that while there are really good providers across the county there are several barriers to engaging, for disabled children and their families, that need to be overcome in order to achieve the impacts and outcomes. These barriers can be seen in the graphic below:

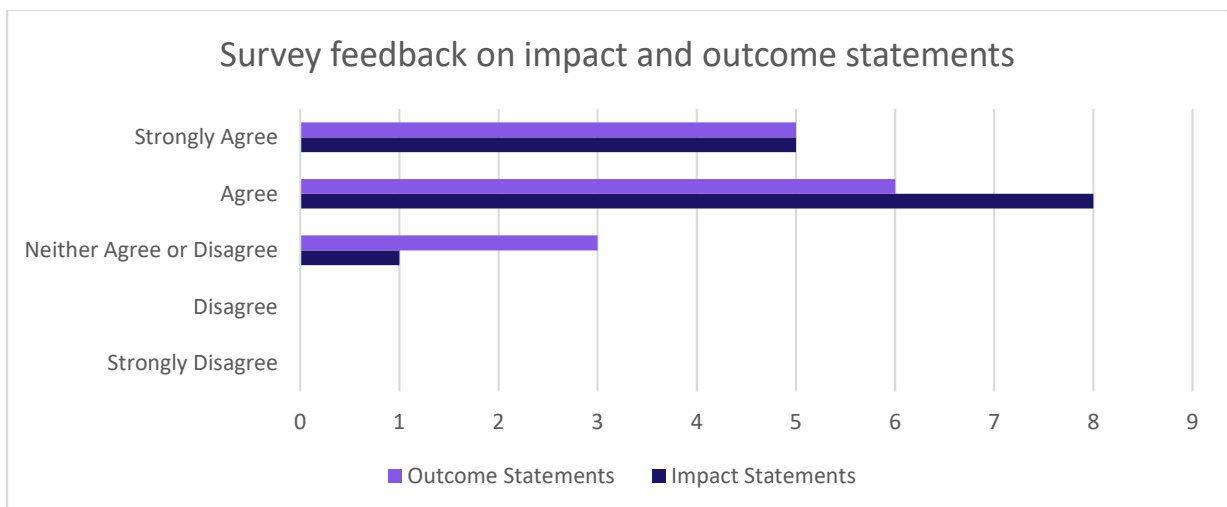


Webinar and Survey

There was limited uptake of spaces at the face-to-face workshops from parent carers, which may be due to issues with capacity and ease of access as well as the timing of the events being close to the return to school and college in September. Therefore, to ensure the views of parent carers were embedded in this co-production process a supplementary webinar with a linked survey was disseminated to capture the views of those unable to attend the workshops.

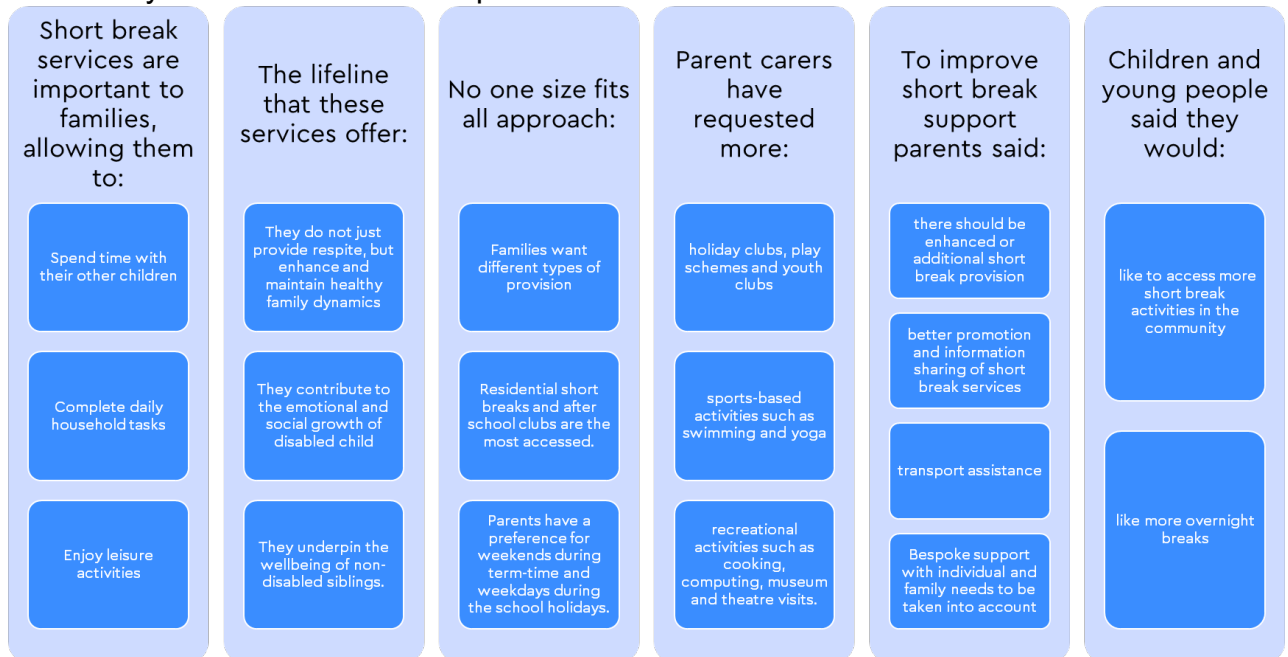
The webinar featured a summary of information on the legal framework for short breaks, examples of good practice from West Sussex and a London Borough and shared the feedback from the face to face workshops outlining the impact and outcome statements that had been developed. At this point, participants were asked to pause the webinar and go to the online survey and give their feedback on the statements that were shared.

The feedback was overwhelmingly those parents and carers responding agreed with the statements that had been created in the session with 92.8% of participants either agreeing or strongly agreeing with the impact statements and 78.6% of participants agreeing or strongly agreeing with the outcomes statements.



Once they had completed this part of the survey, participants were invited to re-join the webinar to hear the feedback that CDC gathered, during the visits to current provision, from children and young people, parent carers and practitioners at the short break services. In addition, a recap of some of the points that have been shared in previous consultation activity was also set out and can be seen in the table below:

After participants reviewed the previous feedback, participants were asked to return to the online survey and answer the final questions.



The first question was whether the current short break services are working well. There was a positive response with over three quarters of respondents (77%) saying yes.

This was accompanied by some qualitative feedback on why the services were working well:

- “This is an opportunity for her to learn new things and have friends. It’s also a nice time for her to enjoy which continues into the school holidays”
- “It is vital to these children to have the chance to get involved and socialise without feeling different, important the parents have a break too’
- “My son loves being able to access the different activities available and he loves being able to explore the outdoor area”
- “Children are happy and have a chance to take part in activities and be independent.”

However, there were also some concerns which were shared by parents who have not had a good experience of the short breaks offer:

- “Too complicated to get a referral”
- “During the pandemic we have had no outside involvement from any professional, our boy is immunosuppressant and has not been taken into consideration for anything that could have helped him or us as a family”

These comments are reflected in some of the barriers and challenges that were mentioned in the face-to-face workshops. The comment relating to the pandemic also highlights the impact of COVID has exacerbated some of the pre-existing inequalities in accessing provision and raises the question of how to ensure that all disabled children and young people can access the support they need.

One respondent to this survey was a social worker for a family-based short breaks service who also raised a concern that the Family Link service does not appear to be receiving the number of referrals they have had in previous years. In addition, recently they have been receiving referrals of children whose needs are over and above what the existing family-based service can support, including children with behaviours that challenge where children are needing 2:1 support. The existing service has a range of carers, including single carers, and this would mean being unable to meet this level of need. Similar feedback was shared in the face-to-face sessions.

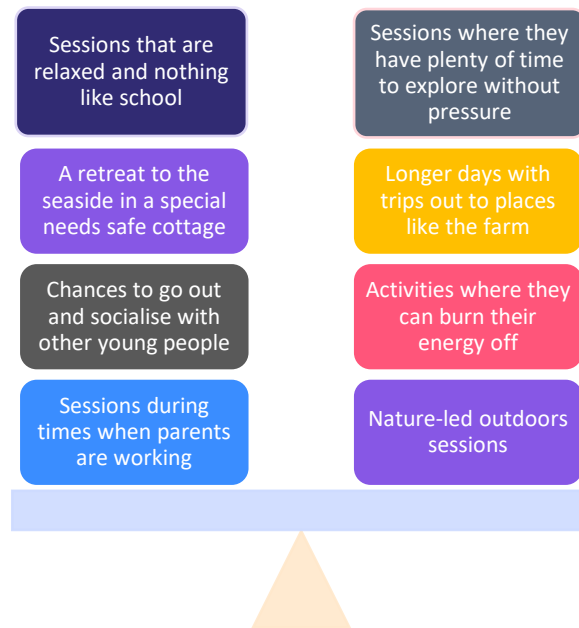
Parent carers were also asked what they would change about the short breaks offer if they could. There were some common responses with four parent carers not wanting any changes to the service they receive, two wanting a wider range of activities, two wanting an increased frequency of days and two wanting slightly longer days to be offered. However, there were also some important individual observations, including one parent wanting there to be sessions on offer nearer to where they live. Additionally, one parent wanted more feedback on what their child actually does at the short break session. They know he is happy but as he is non-verbal they do not always know what he does during sessions

There were also some more specific pieces of feedback regarding personal experiences of the system that were raised;

- One parent mentioned an issue that happened during a trip to Gulliver’s – ‘I said that my daughter does not walk long distances and requires a pushchair. It was decided to go without it but I had to collect her early due to them having to carry her. This has meant that she will now ask to be carried which is not possible as she is too heavy. It’s also the reason we have the pushchair. The repercussions of this day out caused at least a week of wanting to be carried while out on a walk’
- One parent raised that there are currently not enough staff at the provision, so they are having to stay and supervise him

- Another parent stated that they had never been able to actually access a break for their 11 year old son and felt they were having to jump through excessive hoops and red tape

Participants were also asked to tell us about how they would design the perfect short break for their child and while there were variations in the specific options suggested, several key ideas came through.



Ideas and innovation

There were a number of key areas for development identified through both the workshops and the survey feedback. These fitted broadly within three themes of ideas to continue to explore and co-produce. Some of the initial ideas are set out below and link to some of the particular barriers identified as well as to progressing towards the outcomes and impact:



Recommendations and next steps

Low cost, no cost:

- Co-develop a digital campaign to raise awareness of Short Break opportunities and how to access them and promote this through the SEND Local Offer, schools, colleges and community partners
- Establish a short break provider network of both existing and prospective providers to improve:
 - Awareness between providers of the different opportunities available to enable them to effectively sign post families
 - Communication and collaboration between providers
 - Ideas and innovation to help increase the range of activities available
- Review current volunteering infrastructure across the Trust and CCG to identify opportunities to develop this workforce:
 - Explore links with schools and colleges for work experience and volunteering placements to build the future workforce
- Co-design and deliver an information sharing event for families, providers, prospective staff and practitioners supporting families

Longer term investment/action:

- Develop the opportunity for a parent-led engagement programme to support more detailed exploration and design of the ideas set out above with co-production with families embedded in an ongoing way

- Bring together working groups of key practitioners, providers and parent carer representatives to co-design new types of service such as:
 - Buddying support particularly to enable young people to access their communities and prepare for adulthood
 - Flexible and creative opportunities that can respond to the different skills and interests of children and young people
- Build inclusive communities through working with local mainstream providers. This could include:
 - 'buddying' short break providers with mainstream providers
 - Workforce development programme for mainstream providers and staff teams to build disability awareness and inclusive cultures
 - Develop or sign up to a 'disability friendly' campaign and enable local businesses to sign up. This could include a 'compass card' style tier of support