

Family Voice Norfolk Consultation with Parent Carers of Children and Young People with SEND on Short Breaks

Consultation

Parent carers of children and young people with Special Educational Needs and/or Disabilities (SEND) were consulted via an online survey in August 2019 about Short Breaks and childcare provision. This report addresses the Short Breaks aspects of the survey. A further report on childcare provision is also available.

Background

Family Voice Norfolk (FVN) is a collective of parent carers from nearly 900 families across Norfolk and represents over 1,100 children and young people with SEND. FVN has been the strategic voice of parent carers working in partnership with Norfolk County Council (NCC) and the five clinical commissioning groups (CCGs) since 2006. It is funded through a direct DfE grant (administered through Contact), by NCC and by the five CCGs.

Parent carers were invited to complete a questionnaire online and had the opportunity to include comments on their experiences of Short Breaks. The survey ran from 13 to 25 August 2019. FVN received 120 responses.

What did we learn?

While some of our respondents were very happy with their provision and were finding it helpful, many others found that Short Breaks themselves created further difficulties and stresses for the family. Survey responses are analysed below, while comments from parent carers are given in the analysis and in appendices at the end of this report. Four important themes emerged in what parent carers told us:

- All of our respondents and their children or young people with SEND come into contact with professionals of various kinds, but few had found out about Short Breaks by this means. There does not seem to be a consistent and comprehensive way of ensuring that families know that Short Breaks may be available to them and understand how the system works and how decisions are made.
- Many families find the work involved in acquiring and administering Short Breaks quite overwhelming – in fact, an additional stress in lives that are already extremely difficult.
- There is a lack of appropriate support and provision that can be accessed, even when funding has been supplied through Short Breaks. Employing suitable personal assistants (PAs) is very difficult in some areas, and finding help that is sufficiently skilled and flexible is often impossible, while groups are often not appropriate through lack of proper understanding and support for children's and young people's varying needs.
- One result of this is that often activities for children and young people involve the parent carer having to be with them. This is not a break for the parent carer or an experience of independence from parental care for the child or young person.

"We have applied and been turned down for short breaks because my child "isn't disabled enough". ASD, Tourette's, anxiety disorder, hypermobility apparently not enough for them. I am a single parent who is trapped between caring for my sick parent and my child who has been in and out of education for a long time. We haven't had a holiday for ten years and I never get a day off. Who are these short breaks for if not for families like us?"

"It is an unnecessarily complex process which causes unnecessary stress to parents already struggling in difficult situations. Many of us feel that the decisions are arbitrary and based on the whim of the managerial team rather than the evidence provided."

"The system does not currently appear to be needs-based but based on how hard you are willing to fight and how much paperwork you produce."

"Recruiting a PA is extremely time consuming and difficult. Really exhausting. The process is lengthy and full of paperwork (you are essentially employing staff) and is the last thing you need to start doing when you are in a crisis situation. Very isolating."

"I don't think it is a short break/respite if a parent is expected to stay and supervise child due to lack of staff - also this means child does not have the opportunity to form social friendships separate from parent."

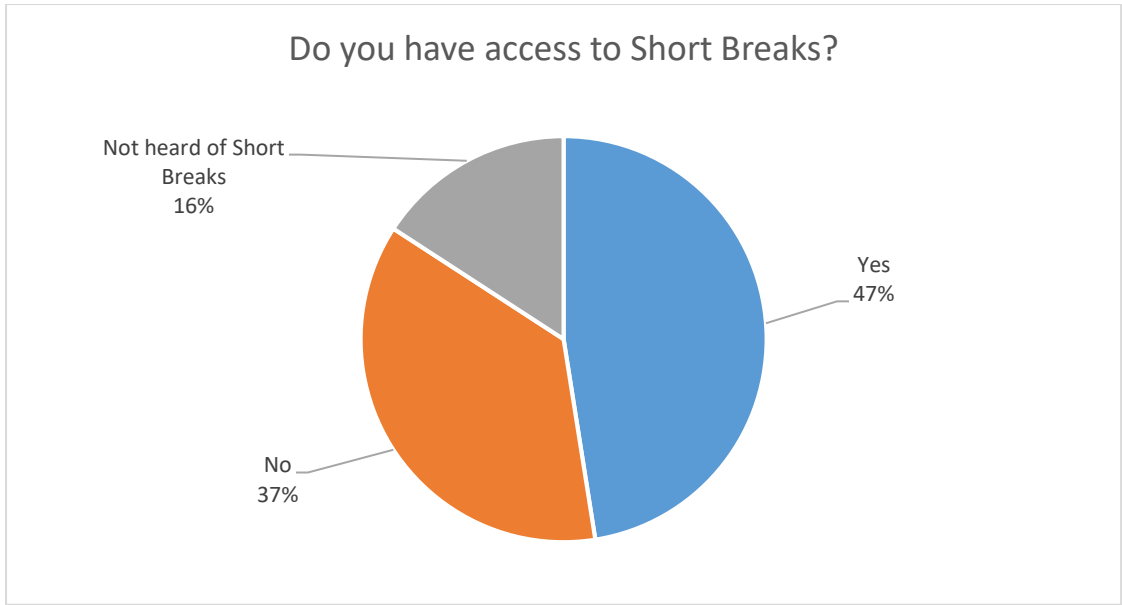
Key messages

- Nearly half of parent carers who took part in the survey have access to Short Breaks.
- A quarter of parent carers rely solely on Short Breaks for respite as they have no other childcare provision at all.
- Parent carers are not finding out about Short Breaks via Local Authority or Health professionals.
 - 31% all parent carers said that they had found out about Short Breaks from other parent carers.
 - Nearly as many parent carers found out about Short Breaks from FVN (7%) as from a Health professional (9%).
 - Only 3% found out about Short Breaks from an EHCP co-ordinator.
- One third of parent carers, who had their package arranged within the last six months, had waited over **six** months to hear back from the Short Breaks team about information on where to find suitable provision for their child or young person.
- 20% of parent carers who have a prepayment card do not fully understand how their card works for them. Adequate training needs to be given to all parent carers before they are in receipt of a prepayment card.
- The use of the prepayment card gathered mixed responses from parent carers. Some said that it gives them greater flexibility, while others said that there is a limited number of places that accept the card.
- Parent carers would prefer to be able to access transactions online to give them greater control over how much has been spent from their prepayment card.
- Three-quarters of children and young people do not have their Short Break provision mentioned in their EHCPs, even though this should be included under section D – Social Care Needs.
- Parent carers mention over and over again that while they have funds for Short Breaks, there is a lack of activities and provision for their children and young people.
- Activities and provision that are available often do not have specialist staff to look after children and young people with SEND, meaning that parent carers are often their child's 1:1. This is not respite for parent carers.
- Many parent carers, especially those new to the world of SEND, are not aware of the Short Breaks system and the respite care available to them.
 - 79% of parent carers who had not heard of Short Breaks said that they felt they were or could be entitled to Short Breaks, if they knew more about the provision available and how to apply;
 - 35% of parent carers who had heard about Short Breaks but did not have them, had not applied or did not know how to apply.

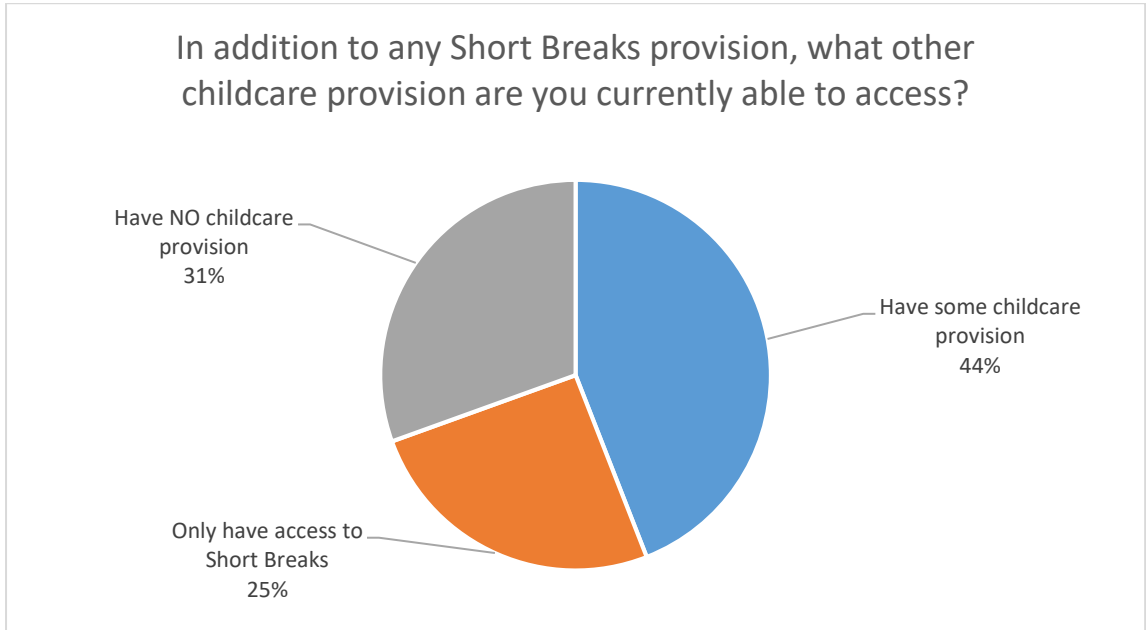
Main findings

Access to Short Breaks

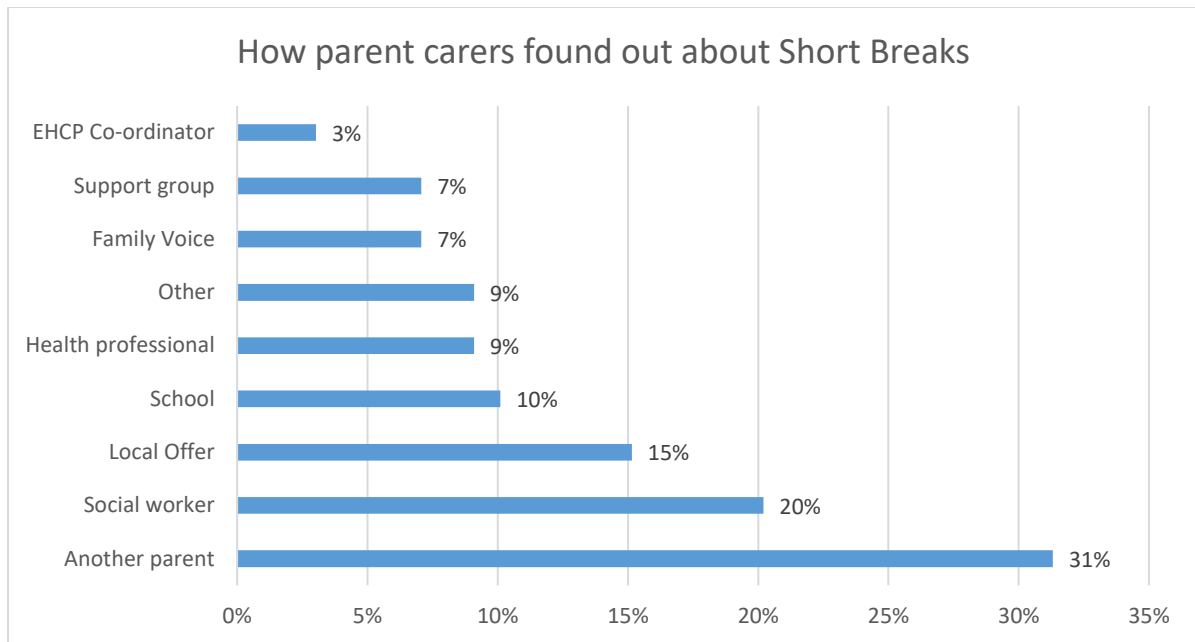
Parent carers were asked if they had access to Short Breaks. Nearly half of all parent carers who responded currently have access to Short Breaks but 16% have never heard of them at all.



Parent carers were asked if they had any childcare provision in addition to any Short Breaks that they received. 31% have no childcare provision at all. Without Short Breaks, a further 25% would have no childcare provision.

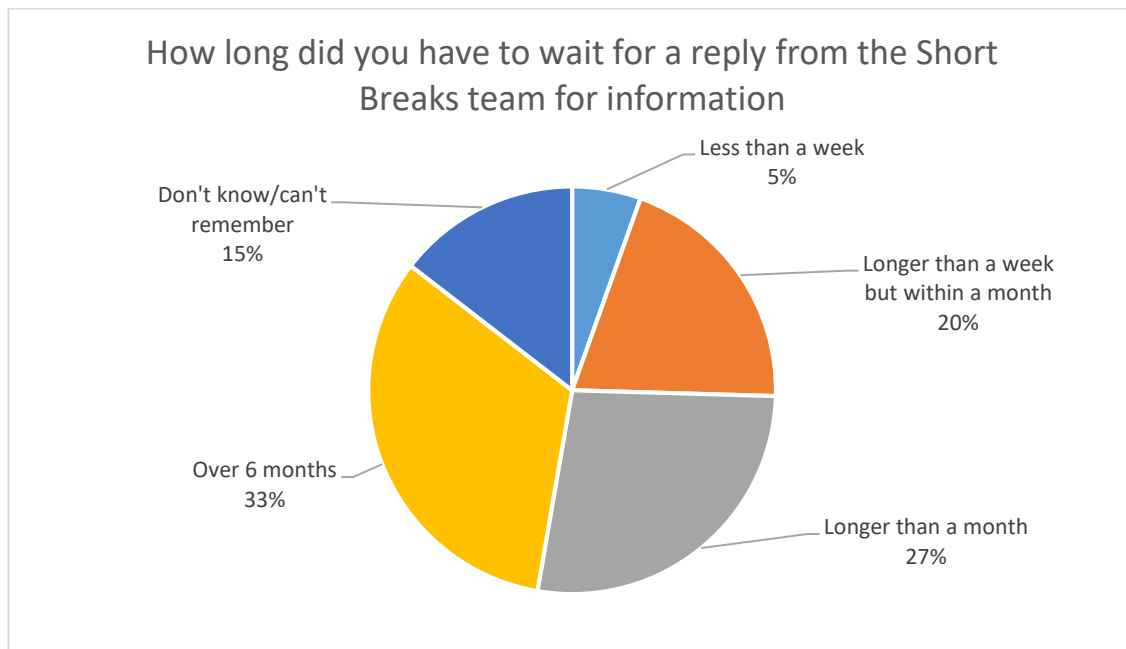


Nearly a third of all parent carers (31%) said that they had found out about Short Breaks from other parents. This is ten times the number than those that found out from an EHCP co-ordinator (3%). Nearly as many parent carers found out about Short Breaks from FVN (7%) as from a Health professional (9%). Those that answered “other” mentioned the internet, coffee mornings or place of work. Parent carers were able to choose as many options as they wished so the total adds up to more than 100%.

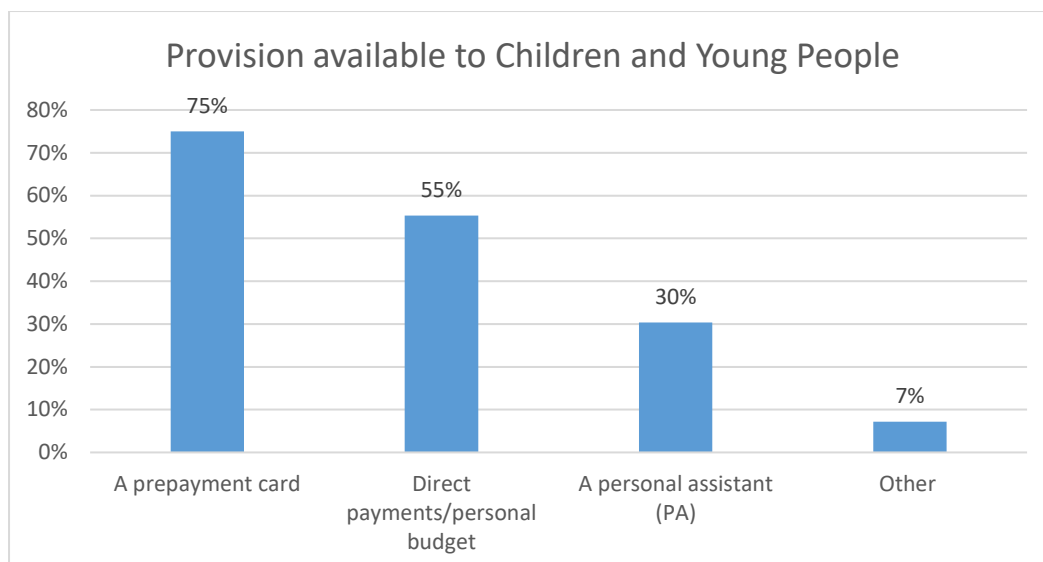


Responses from here on in this report relate only to the parent carers who have access to Short Breaks. This is a smaller cohort of parent carers and relates to 57 responses.

Parent carers were asked, if their package was organised within the last six months, how long they had to wait for a reply from the Short Breaks team for information on where to find suitable provision for their child or young person. Just over half of all parent carers who have Short Breaks have had them organised in the last six months. One third of these parent carers had waited over **six** months to hear back from the Short Breaks team about information on where to find suitable provision for their child or young person.



Parent carers were asked if they received direct payments/personal budget, a prepayment card and/or a had a personal assistant. Parent carers were able to choose as many options as applied. 75% had a prepayment card and 30% had a personal assistant.



17% of parent carers have not been able to recruit a PA. Parent carers say that it is difficult to recruit and retain PAs, mainly because there are no adequately trained PAs in their area who have the flexibility to work around the family's requirements. Parent carers that cited there were no PAs in their area came from North, South and East Norfolk. The stress of recruiting a PA puts off many parent carers. Parent carer comments are below.

Comments from parents:

"Didn't know where to look, PA register on NCC either didn't work, or when I finally managed to get on it, there were four entries only one actual PA. Where do you look to find a trusted person to look after the most vulnerable in society? We were without a PA for eleven months, it's all very well being given a budget but NCC need to help more with having some trusted people, there is already too much stress on families."

"Previously had budget for PA but could not find anyone suitable so changed to prepaid card."

"Process of recruiting PAs is an absolute nightmare for families."

Three-quarters of parents have opted for a prepayment card that allows them to pay for activities directly. However, over 20% of these parent carers do not fully understand how their prepayment card works for them. Adequate training needs to be given to all parent carers before they are in receipt of a prepayment card.

Parent carers were asked if there were age appropriate activities for their child or young person within a 10-mile radius and beyond. 30% said there were activities within 10 miles of their home and 56% said there were suitable activities over 10 miles from their home.

Activities within 10 miles	Activities over 10 miles			Total
	Yes	Not sure / partly	No	
Yes	28%	2%	0%	30%
Not sure / partly	23%	19%	9%	51%
No	5%	2%	12%	19%
Total	56%	23%	21%	100%

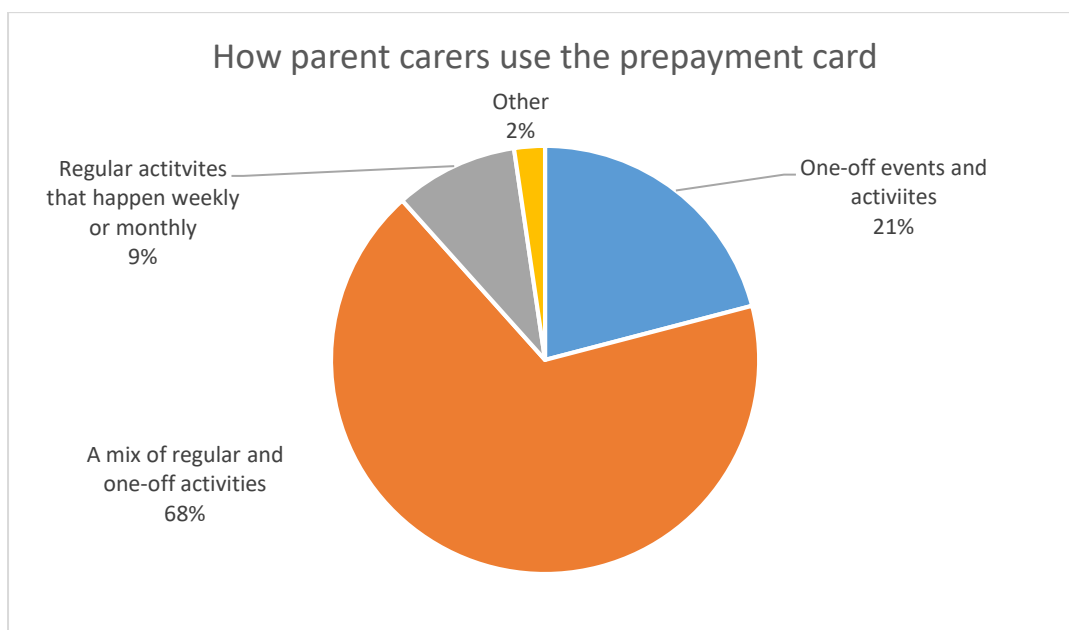
Comments from parent carers:

"My child struggles to want to attend age appropriate activities due to anxiety/ADD and would really benefit from an independent peer other than me in the years ahead to be able to continue accessing scouts, football etc. We are not aware of any one providing such a service in Norfolk."

"We travel within Norfolk for lots of activities but this does become quite exhausting in the summer holidays."

"I haven't been able to find anything suitable for our 17 year old."

The chart below shows how parent carers are using the prepayment card with 68% of parent carers having a mix of regular and one-off activities. "Other" represents parent carers that have the card but are not currently using it.



The use of the prepayment card gathered mixed responses from parent carers. Some said that it gives them greater flexibility, while others said that there is a limited number of places that accept the card. The card only covers the child and often families are unable to afford for the whole family to be included in the activity. Parent carers would prefer to be able to access transactions online to give them greater control over how much has been spent. Below are some comments from parent carers. Further comments are in appendix A on page 11.

Comments from parent carers:

"We like this part of the short breaks provision- it's worked well for us and is very flexible."

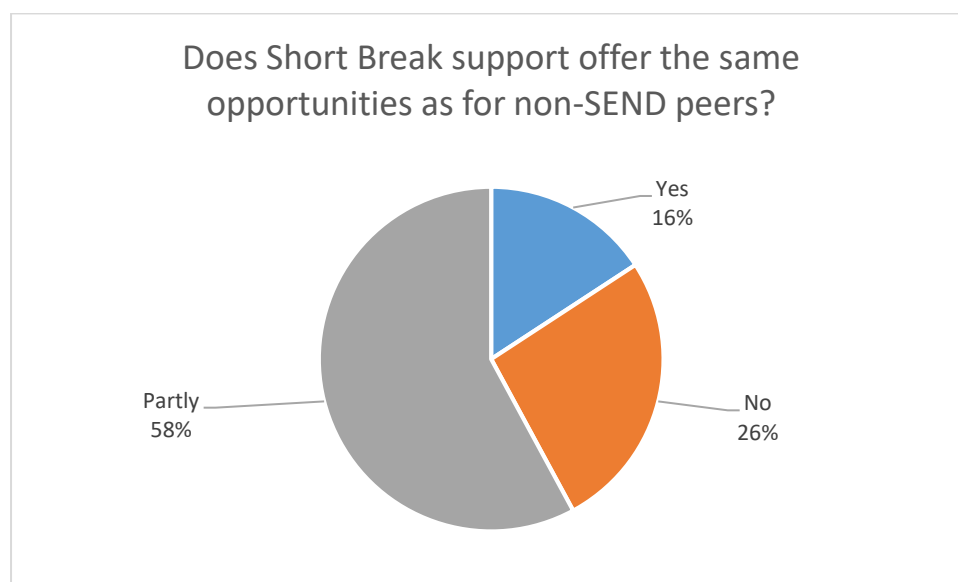
"As my son has very limited interests it's a shame the card is only payment to access places."

"It would be really helpful if we were able to use the card during school hours. We home educate as our child is unable to manage school or busy places. This limits what we can use the card for as we are unable to attend places like the dinosaur park during school holidays, as it is too busy."

"I thought the lady I dealt with in the Short Breaks team was very good, professional, understanding and knowledgeable."

Parent carers were asked if the current Short Breaks support allowed their child or young person to have the same opportunities as their non-SEND peers. Only 16% said that they felt the Short Break support offered them the same opportunities as non-SEND peers while 58% said this was partly the case. Many parents said that while Short Breaks covered some of their child's activities, they still had to attend to be the child's one-to-one. This is not respite for parent carers.

The complexity of needs often meant that children and young people could not be offered the same opportunities as non-SEND peers. Below are some comments from parent carers. A full list of comments is in appendix B on page 12.



Comments from parent carers:

"Whilst the short breaks fund my son & I activities to enjoy & I wouldn't otherwise be able to afford, neither of us are having a break from each other's company and he isn't able to expand his social life/network."

"It does not give the same opportunities as child will not engage but it certainly helps."

"Our son has weekly swimming lessons alongside non-SEND peers."

Three-quarters of children and young people do not have their Short Breaks provision mentioned in their EHCPs, even though this should be included under section D – Social Care Needs. See appendix C on page 14 for comments.

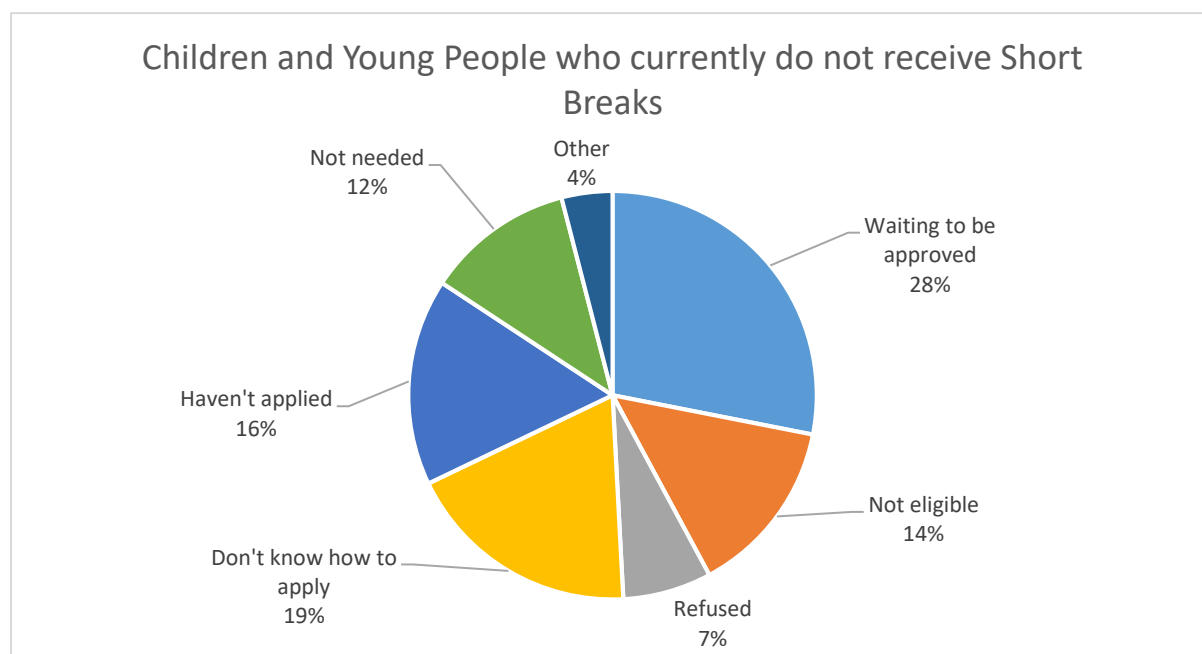
This question asked parent carers who had never heard of Short Breaks if they felt their family might be entitled to them. Before the question was a brief description of Short Breaks taken from the Local Offer, a link to find out more and an email address to contact the Short Breaks team.

There were 19 parent carers in this cohort. Only 21% said no, they did not think their families were entitled to Short Breaks. The remaining 79% said that they felt they were or could be entitled to Short Breaks, if they knew more about the provision available and how to apply. There was only one comment from a parent carer saying, "I would love to go on a family holiday; my son would love it as he has autism."

The final question asked parent carers who had heard of Short Breaks but did not currently receive them, why they did not receive them. There were 43 parent carers in this cohort.

Over a third of these parent carers (35%) said that they either have not applied or did not know how to apply. One comment reflected the views of many:

“I struggle with paperwork and being able to fill in the information they are asking for. Plus, also it's not classed as a priority at the moment when I'm desperately trying to secure my child a school place through a pointless EHCP. My time needs to be spent elsewhere. It's just another battle I don't have the energy for.”



Final Comments from parent carers

There are many common themes from parent carers, which include:

- Many parent carers are not aware of Short Breaks provision;
- Applying for Short Breaks is a lengthy and complicated business, especially for parent carers who are struggling with everyday life;
- Parent carers mention over and over again that while they have funds for Short Breaks, there is a lack of activities and provision for their children and young people;
- Activities and provision that are available often do not have specialist staff to look after children and young people with SEND, meaning that parent carers are often their child's 1:1. This is not respite for parent carers;
- There is a specific lack of activities for young people over the age of 17.

Below are comments from parent carers. Please refer to appendix D on page 15 for a full list of comments.

Comments from parent carers:

"We have applied and been turned down for short breaks because my child "isn't disabled enough". ASD, Tourette's, anxiety disorder, hypermobility apparently not enough for them. I am a single parent who is trapped between caring for my sick parent and my child who has been in and out of education for a long time. We haven't had a holiday for ten years and I never get a day off. Who are these short breaks for if not for families like us?"

"It is an unnecessarily complex process which causes unnecessary stress to parents already struggling in difficult situations. Many of us feel that the decisions are arbitrary and based on the whim of the managerial team rather than the evidence provided."

"Recruiting a PA is extremely time consuming and difficult. Really exhausting. The process is lengthy and full of paperwork (you are essentially employing staff) and is the last thing you need to start doing when you are in a crisis situation."

"Whilst good, it's not very clear how the RAS scoring is assessed as my score was dramatically different to the end award, when I asked to discuss how it was scored the lady basically told me to 'take it or leave it'."

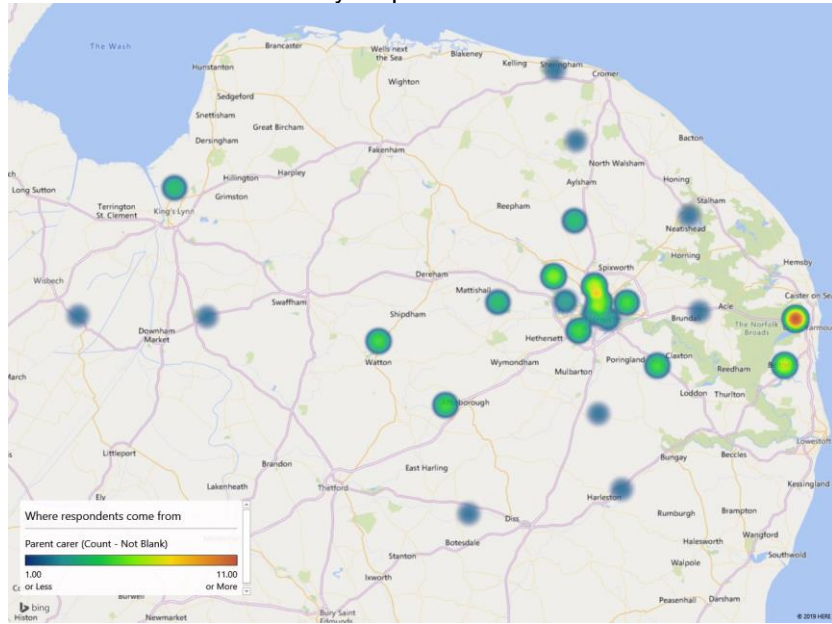
"Short breaks offer no REAL support for us. Some fun activities here and there - great. But what is really needed isn't offered - guidance with autism and different stages of puberty, support to a parent to be able to cope, practical help during tough times. When you're overwhelmed you're not going to feel like heading out on a fun activity."

120 parent carers were surveyed and their responses represent 125 children and young people.

	Mainstream	Special	Early Years	Home Schooled	Other	Total
0 to 4 years old	1.6%		4%	0.8%		6.4%
5 to 11 years old	30.4%	17.6%		2.4%		50.4%
12 to 16 years old	9.6%	20.0%		4.0%	1.6%	35.2%
17 to 21 years old	2.4%	2.4%			0.8%	5.6%
22 to 25 years old					2.4%	2.4%
TOTAL	44%	40%	4%	7.2%	4.8%	100%

However, when looking at the age range and educational setting of those children who currently receive Short Breaks, 90% have children between 5 and 11 years old. 61% attend special school and 33% attend mainstream.

Postcode locations of survey respondents



While locations of respondents were represented from most postcode areas within Norfolk, there was a higher number of responses from the Norwich and Great Yarmouth areas.

Appendix A – Comments about prepayment cards

- As my son has very limited interests it's a shame the card is only payment to access places
- Conflicting information given about paying for a carer /concession ticket along with the child's.
- I thought the lady I dealt with in the Short Breaks team was very good, professional, understanding and knowledgeable.
- I use it to pay for holiday club as well as days out etc.
- It is early days as we have only recently received the card.
- It works very well for us
- It would be really helpful if we were able to use the card during school hours. We home educate as our child is unable to manage school or busy places. This limits what we can use the card for as we are unable to attend places like the dinosaur park during school holidays, as it is too busy. Home education does not take place just between the hours of 9-3:15 and we always home educate at the weekends and through the school holidays as that is a better time for us to be at home, to avoid the busyness. We tend to have family days out/short breaks during term time but are unable to use the card for this as we are not allowed to use it during term time.
- It's been brilliant but I do think that there should be more supported sports clubs for children with SEN
- Last year I literally used £4.60 on it as there are 6 of us in the house and do not have the amount available to us to pay for all 6 of us to use it
- Need more information on places that take it some haven't liked paying with two cards especially if event is busy
- Need more of a range of activities and flexibility for what card can be used for.
- Not a lot spent on activities where I can leave him - as they just aren't available in the area.
- On online, at a glance, statement of account would be advantageous.
- Once set up the cards are good to use but they are complicated to set up and random payments have gone out of our account from the council without them telling us. Plus the accounting of the card on the statement is very unclear.
- Really easy to use as long as the services you access take card payments.
- Short breaks should not be funding cinema trips, zoo tickets, merlin passes etc., via pre-payment cards. This is rewarding a child for being disabled. These should be paid from DLA, family fund applications, parental responsibility rather than short breaks budget. Proper, appropriate commissioned services giving young people & families a break are needed.
- Still have to pay for other family members or carer so many attractions too expensive.
- The prepaid card allows for direct payment for services for which I also upload an invoice. Payment is made straight away without review. So then I worry in case it isn't actually approved and I'll have to pay it back.
- We like this part of the short breaks provision- it's worked well for us and is very flexible
- Works well in conjunction with PA, helps my son learn to budget

Appendix B – Comments from parent carers when asked if they felt that the current short break support allows your child or young person to have the same opportunities as their non-SEND peers

Parent carers who responded "No"

- 1. Not enough of the services can provide 1-1 support
- 2. A lot of the services rely on volunteers - this can mean lack of consistency of staffing levels, inadequate training (also from personal experience volunteers can only wanted to work with children who do as they are told and follow instructions - my daughter was told she could not return to a special needs group because she did not sit down and do the activities for the whole time)
- 3. Services are being cancelled due to lack of funding
- 4. A lot of the services are for children with mild/moderate learning difficulties. Very few can (or want to) cater for children with severe learning difficulties
- 5. Not all services have sufficient first aid experience or confidence
- 6. I don't think it is a short break/respite if a parent is expected to stay and supervise child due to lack of staff - also this means child does not have the opportunity to form social friendships separate from parent
- In holidays places are crowded and queues are long
- More for social skills for teenagers
- No access to providers as needs too high - restricted to Direct Payments
- Nothing can make my son have opportunities same as non-SEND child
- Only because his disabilities don't allow for this
- Parent is always in attendance. Whilst the short breaks fund my son & I activities to enjoy & I wouldn't otherwise be able to afford, neither of us are having a break from each other's company and he isn't able to expand his social life/network
Out of school activities just don't cater for children with complex cognitive needs.
- The funding and the way it is organised means we are not able to pay for the one to one support she needs to access mainstream activities/clubs, which means that as the parent I have to one to one her, which doesn't give me a break. Also if I cannot 1to1 then she cannot do it.
We desperately need respite care, this has been identified by various professionals, but we seem to be unable to access this through Norfolk.
- There are no childcare/child minding facilities. I am struggling to find somewhere I can leave my child over school holidays
- There are no sports clubs running SEN camps like they do for all other kids
- There is a good service setting up short breaks but actually the rest of it you have to manage yourself. If there are technical issues they can help, but just trying to get support for everyday activities does not happen.
- Too few opportunities to access within acceptable distance, therefore not able to benefit from activities.

Parent carers who responded "Partly"

- Activities still require my supervision
- Allows for extra support to be arranged.
- My child is reluctant to go to activities that the card can pay for so we have at times paid for things and then he's not been willing to go.
- At the age my child is now, her mainstream peer group would go out without a responsible person, my child is too vulnerable
- Can't get a PA regularly.
- Child treated differently not equal
- He can't have the same opportunities; it wouldn't be safe. We do the best we can
- I am extremely grateful for the £500. With my child's SEN, getting her to take part in additional activities is very difficult. It is not enough money to pay for an

assistant but it does give us the opportunity to try other activities but not on a par with her peers.

- I'm not sure what you mean by non-SEND peers. Typically developing peers? I just feel our son needs support which Short Breaks won't cover i.e. occupational therapy to learn to shave, enough funding to cover a PA to take him to the gym.
- In order to get the amount that is indicated by the resource allocation system, you have to provide reams of evidence and if you disagree with the amount offered, you hit a brick wall of refusal. The system does not currently appear to be needs-based but based on how hard you are willing to fight and how much paperwork you produce.
- It does not give the same opportunities as child will not engage but it certainly helps.
- It enables him to continue at cubs with a PA as he would be unable to without. But he shouldn't need the PA there in the first place as they could cope with him in Beavers (it's down to abilities of the leaders not his needs)
- It's difficult to get a space.
- Not enough flexibility in budget and provision but also activities for children who do not want to attend clubs /day venues /not active and have difficulty wanting to try things or do things on regular basis.
- Really struggled to get a PA, took months, hopefully now we have recruited it should work as meant to.
- The money is welcome but there are not enough inclusive activities available to access.
- We have not been awarded enough to last a year of something weekly
- Would work much better if we could get PA to work hours we need. We have been given a bigger budget this year (one off because my husband has been very ill) but usually we don't get enough
- Young person unable to attend at the moment as anxiety too extreme, however, the provider does offer good support and activity. The overall environment and number of peers is too overwhelming.

Parent carers who responded "Yes"

- My child can access activities with someone other than mum or dad
- Only because of overnight respite
- Our son has weekly swimming lessons alongside non-SEND peers. He is also able to access other activities such as trampolining

Appendix C – Comments from parent carers about EHCPs and the inclusion or not of Short Breaks

Comments from parent carers where Short Breaks are NOT in the EHCP

- At the time the EHCP was compiled we were not accessing Short Breaks as our son didn't meet the then criteria. At the most recent review, our coordinator mentioned Short Breaks and it was after this meeting that we applied
- EHCP coordinator told us nothing should be written in social care section
- EHCP doesn't mention short breaks
- I am not sure that there is any connection between the two.
- I didn't realize they could be
- I spoke about it at review it was just added into the comments that he had short breaks, was told it was not relevant to the EHCP
- I've repeatedly asked about this but social worker fails to attend the EHCP meetings
- It is not in our EHCP
- Never discussed
- No one mentions them
- Not aware of it being in the plan
- Not considered at all
- Not even mentioned in our rubbish plan.
- Not mentioned
- Nothing about what my child does outside of school
- Nothing mentioned in our EHCP plan about short breaks
- Ours is currently separated but it might get integrated next year when our son moves to a special school
- Provided through fostering agency
- Short breaks have never been discussed during an EHCP meeting or review. I applied independently & was successful following a Family Voice information workshop approx 2 years ago.
- Short breaks is not mentioned in our child's EHCP but our child still doesn't have a final plan a year and a half after applying.
- Short breaks was mentioned in the annual review but not included in plan
- The EHCPs are not getting updated at the moment so the yearly updates for the Short Breaks don't get included. The schools don't automatically put it into the EHCP reviews but they are unclear what to put.
- They are not mentioned in the EHCP, I had to approach Short Breaks directly
- We never had a social assessment when we had our EHCP
- We were never told about Short Breaks despite ASD diagnosis, EHCP, 3 annual reviews and 2 tribunals - only heard through a friend.
- I don't think that they are included, because we have a separate Child in Need Plan

Comments from parent carers where Short Breaks are in the EHCP

- It is mentioned that short breaks has been applied for to increase independence away from immediate family
- It's just mentioned that he has weekly external music lessons - that's it! Just a mention.
- Just says Short Breaks receipt. It does not specify budget or what it provides (and that was only after AR).
- Mentioned in terms of budget/number of sessions and provider. No direct explanation of her needs.
- Only listed in EHCP because I insisted they should be documented in the EHCP
- The EHCP simply states our son gets £1,000 per year for social activities and lists them.

- There is a paragraph listing that she has them, and what they are used for

Appendix D – Final comments

Comments from parent carers who have not heard of short breaks

- Help with applying knowledge of what actually we can access to help us as a family

Comments from parent carers who do not have short breaks but have heard of them

- BREAK were awful would love to put in full description but can't
- The criteria is often too high and unlawful. Not very well advertised for new parents coming into the world of SEND.
- Haven't been given enough information to comment not sure if true was told social services are involved in the short breaks scheme
- I am currently working however it is becoming very difficult and effecting my work with phone calls, my mum is the only other person who is able to look after child and she is now exhausted.
- I don't know of any short breaks stuff which is suitable for my young person, high functioning ASD... he needs interesting and challenging things to do, and hates being around people who he perceives as "weird" i.e. with a disability. He loves movie making, sound hi tech stuff, and I can't ever find anything like this. Plus activities are very Norwich focused, which is unrealistic to travel to from where I live.
- It isn't widely known about and GDPR has made this worse
- It would help if they could be accessed via Early Help or other professionals and it was not up to the parent to apply and submit evidence
- Short breaks are not accessible for everyone, you are not told they're available.
- Taking a long time to hear from short breaks application
- The provision is awful
- There is not any.
- We have applied and been turned down for short breaks because my child "isn't disabled enough". ASD, Tourette's, anxiety disorder, hypermobility apparently not enough for them. I am a single parent who is trapped between caring for my sick parent and my child who has been in and out of education for a long time. We haven't had a holiday for ten years and I never get a day off. Who are these short breaks for if not for families like us?

Comments from parent carers who have short breaks

- Great system. However, treat as a family. Allow family members to support with help
- I am writing this as a parent who has received a reasonable level of funding: I think that the current Short Breaks system is not fit for purpose. It appears that everyone is offered £500 initially and only gets more if they fight for it. It discriminates against children without a formal diagnosis or without an EHCP. It discriminates against parents who are unable to fill out forms, navigate a complex system or understand what they are entitled to. There appears to be no formal complaints or appeal system and if there is then it is very well hidden. It is an unnecessarily complex process which causes unnecessary stress to parents already struggling in difficult situations. Many of us feel that the decisions are arbitrary and based on the whim of the managerial team rather than the evidence provided.

- Short breaks broke down with NANSAs earlier this year due to my child's needs. It is possible that there is one provider able to meet my child's needs but that is by no means certain and they are full anyway. My child needs significant support. Recruiting a PA is extremely time consuming and difficult. Really exhausting. The process is lengthy and full of paperwork (you are essentially employing staff) and is the last thing you need to start doing when you are in a crisis situation. Very isolating.
- It would be good if there were activities for mainstream children with SEND adaptations. As we have suddenly found we can't access any age appropriate activities.
- It's wonderful but I would definitely like to see more PAs and SEN after school clubs and school holiday activities, my son has been removed from tots to teens days because they refused to deal with his toileting needs.
- More support for working parents
- Short breaks we use are superb, he loves going but it's 40 min drive away and not flexible times
- Specialised care is too hard to find!
- That it covers activity costs for the young person only. But they can't attend something unless their carer goes too. So we end up not doing things. Also, carers get really worn out. There isn't any support for us. Sometimes I wish I could just die as I get so overwhelmed. Never have I been asked if I'm coping. Short breaks offer no REAL support for us. Some fun activities here and there - great. But what is really needed isn't offered - guidance with autism and different stages of puberty, support to a parent to be able to cope, practical help during tough times. When you're overwhelmed you're not going to feel like heading out on a fun activity.
- This would be life changing for our family. I'm so happy this is finally being considered!
- We are struggling to work out the best way to support our daughter with her social life/in the community so that she enjoys herself and we achieve some respite. The thought of organising, interviewing and managing PA's is, quite frankly, overwhelming, especially when, as parents, we are exhausted and drained. It feels like we have to work very hard for every drop of help/ budget on offer. More advice is needed on the various options available. With a full explanation of how the different choices on offer work.
- Whilst good, it's not very clear how the RAS scoring is assessed as my score was dramatically different to the end award, when I asked to discuss how it was scored the lady basically told me to 'take it or leave it'. I think the scoring and award system needs to be clearer and more open.
- Why is it so hard to access respite? How do you go about getting a carers assessment when caring for a child?