

## **Family Voice Norfolk consultation on new Short Breaks Service from Norfolk County Council Children's Social Services**

### **Consultation**

Parents of children and young people using or wanting to use Norfolk County Council Children's Social Services new Short Breaks service were consulted via an online survey during the summer of 2017 to inform this paper.

### **Background**

Family Voice Norfolk (FVN) is a collective of parent carers from over 700 families across Norfolk including the Great Yarmouth and Waveney area. FVN has been the strategic voice of parent carers working in partnership with NCC and the CCGs since 2006. It is funded through a direct DfE grant (administered through Contact) and by Norfolk County Council.

Each of our members was invited to complete a questionnaire online and had the opportunity to write comments on their experiences of the existing service after each question. We had 47 responses to our questionnaire that have informed this survey. Individual comments are provided in the Appendices.

### **Key messages**

Key messages coming out of the discussion on Short Breaks:

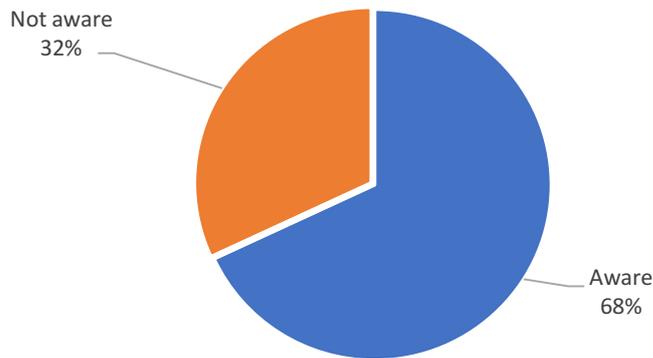
- Families really value having access to Short Breaks;
- Parents want to be involved in completing the Resource Allocation System (RAS) questionnaire;
- Parents would like more time to complete the RAS questionnaire and want a clearer, more understandable questionnaire that covers all C&YP with SEND;
- Parents want a system to meet the needs of all SEND C&YP; they felt the questionnaire was biased away from ASD towards provision for C&YP with physical and more complex needs;
- Parents believe the system should be transparent, fair and equitable; they want to know what the criteria, potential budgets and timeframes are for decisions;
- A third of parents who responded were unaware of the RAS questionnaire;
- Of those parents who had complained, two thirds were successful in improving their child's allocation;
- Parents want more information on how they can spend their allocation, what provision is on offer, and its cost;
- The introduction of the new scheme was too hasty;
- Parents' perception was that the new system was created to save money.

### **Section A – Resource Allocation System (RAS) Questionnaire**

**Are you aware that a Resource Allocation System Questionnaire (RAS) must be completed as part of your Short Breaks application or renewal?**

47 parent carers responded to this question. 32 (68%) parent carers were aware that a RAS questionnaire had to be completed and 15 (32%) were not aware that the RAS questionnaire had to be filled in as part of the Short Breaks application or renewal.

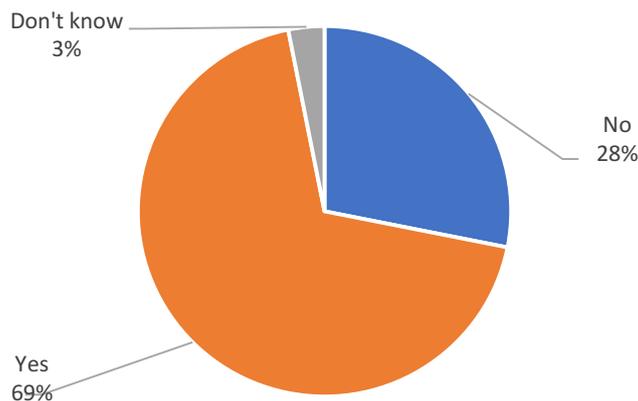
Percentage of parents who were aware that a RAS questionnaire must be completed as part of the Short Breaks application or renewal



**If you were aware of the RAS questionnaire, were you involved in filling it in?**

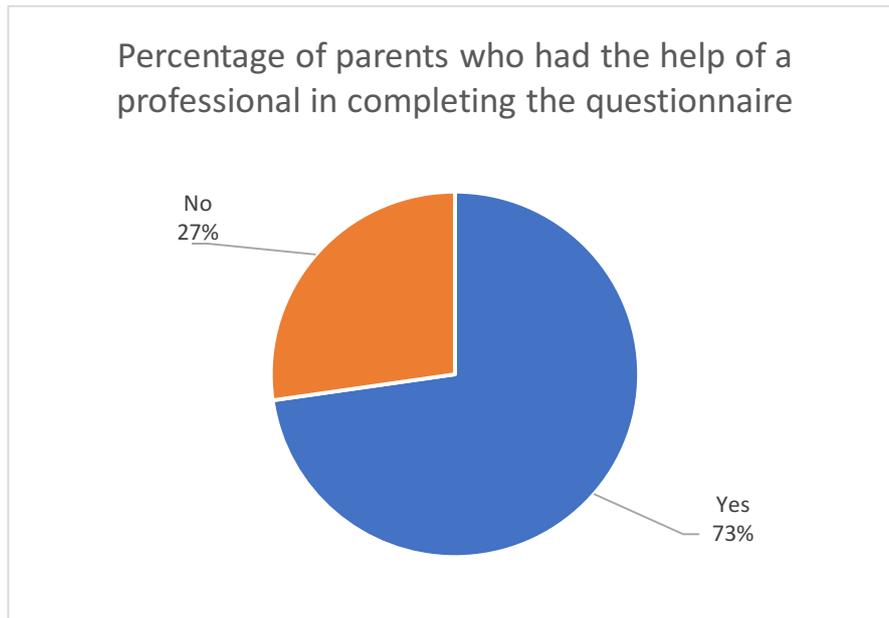
Out of our 47 parents' responses, only 32 were able to answer this question. 22 (69%) parent carers were involved in filling in the questionnaire, 9 (28%) were not involved and 1 did not know.

Percentage of parents who were involved in filling in the RAS questionnaire



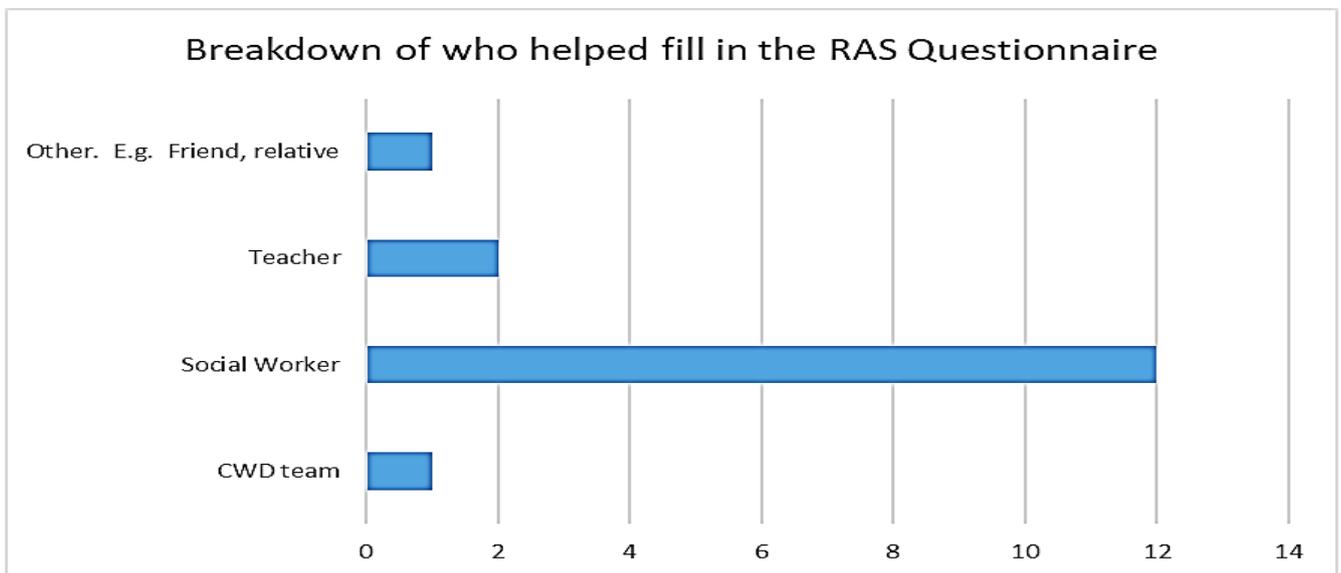
**Was your RAS questionnaire completed with the help of a professional?**

Of the 22 parent carers who were involved in filling in the RAS questionnaire, 16 (73%) had help from a professional and 6 (27%) did not receive any help.



**Please tell us who helped you to complete it?**

When parents had help to fill in the RAS questionnaire it was provided by the following professionals:



**Were you confident that they understood how to fill it in?**

10 parents had confidence in the professional helping them.  
6 parents had no confidence in the professional helping them.

### Were your views and thoughts listened to?

9 parents thought they were listened to.  
2 said No, they did not feel listened to.

Please tell us who helped you to complete it:	Were you confident that they understood how to fill it in?	Were your views and thoughts listened to?
CWD team	<i>"No, I had sent lots of evidence, but we were only offered a very low amount."</i>	<i>"Yes, completely but I had to challenge the allocation, I was not asked for my thoughts."</i>
Other. E.g. Friend/relative	<i>"Not really"</i>	<i>"Sometimes"</i>
Social Worker	<i>"No - Social Worker commented that some questions were unhelpful in the RAS and was not always sure of the correct category to put my child in."</i>	<i>"Not initially - the whole experience was very upsetting and the social worker stated my child had to move to the lowest category of need if there was disagreement over which one he fitted in. We felt that the social worker made assumptions about our child's needs and did not listen even when we offered evidence to show that their assumptions were incorrect."</i>
Teacher	<i>"The teacher had no experience of the questions but was very helpful."</i>	<i>"I am still waiting to be allocated with a social worker having scored my child quite high and need to have an assessment."</i>

The way the questions were worded meant that only parent carers who were aware of the RAS questionnaire were asked if they were involved in filling it in and, of those, only parent carers who were involved in filling in their RAS were asked about the help they had, the confidence they had in that help and if their views and thoughts were listened to. To see this diagrammatically, please refer to Appendix A.

### What did you think of the questions in the RAS questionnaire?

Parents' comments were quite negative about the questionnaire. See Appendix B for all the comments from parents.

*"They were difficult to answer for my child"*

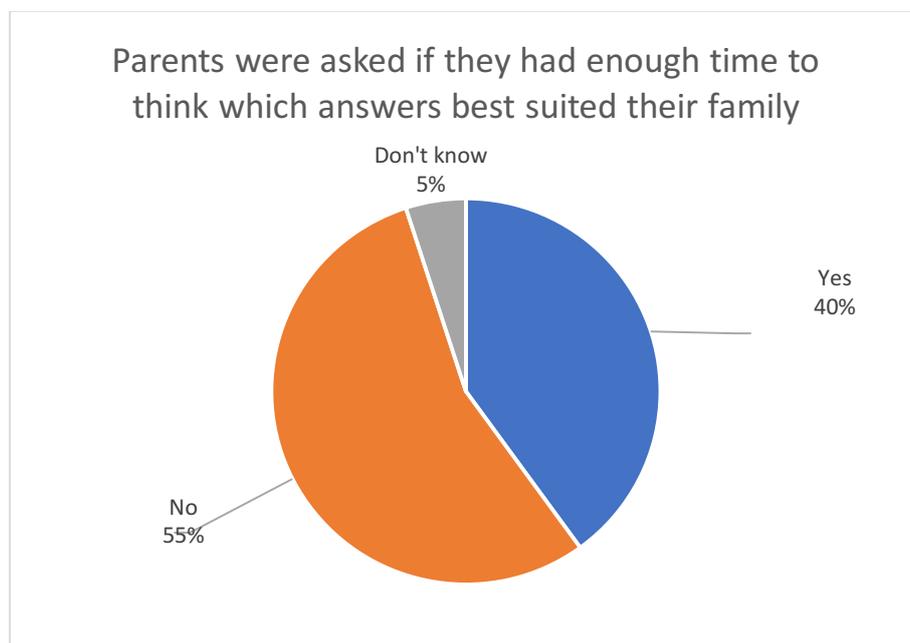
*"They only took account of the child not the whole family"*

*"Seems to score you less the more you do for your child"*

*"Very directed questions, not good and not designed for my children with ASD or many other issues"*

### Did you have enough time to think which answers best suited your family?

In order to answer this question, parent carers had to answer 'yes' to whether they were aware that the RAS had to be completed AND whether they were involved in filling it in. There were 20 responses and 11 parent carers said they did not have enough time to think which answers best suited their family. Eight families said yes, they did have enough time.



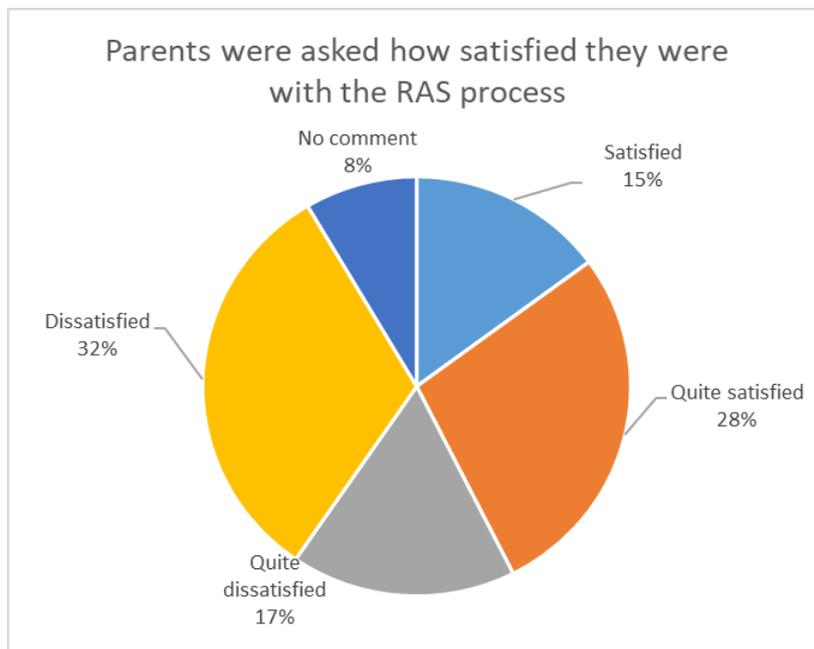
### How long did you have to wait to hear whether your application had been successful?

30 parent carers responded to this question. Nearly a quarter received a response about the success of their application straight away. Another quarter had to wait between 4 and 12 weeks. Please refer to Appendix C for further comments on this question.

Wait times to hear about application	No. of responses	Percentage
Straight away	7	23.3%
Less than a month	6	20.0%
4 to 12 weeks	8	26.7%
Long time	3	10.0%
Still not heard	3	10.0%
Not submitted yet	2	6.7%
Don't know	1	3.3%

**Please rate your overall experience of this part of the process?**

47 parent carers responded to this question. 20 (43%) of parent carers were satisfied or quite satisfied with the RAS questionnaire process, while 23 (49%) were dissatisfied or quite dissatisfied.



**Could you tell us what was good about your family’s experience of the RAS questionnaire process and what could be improved?**

**What was good:**

*“It is good that it helps a family to focus on what the purpose of short breaks is and make sure they are accessing the best options for their child and themselves. It is also good to have an awareness of the cost of provision.”*

**What is bad:**

*“The new process seems to have been brought in too quickly with very little explanation and professional support. Our experience was a significant drop in provision which we challenged and saw an increase that we are happy with but not back to the level of previous years, even though my child's needs are increasing as they get older. The whole process was emotionally difficult and time consuming. Many parents/carers would not be strong enough to question their outcome. It felt like another example of having to make a bit of a fuss just to receive what is needed and if you don't have the ability to do this you lose out. This is not equality. “*

Please refer to Appendix D for further comments.

**How to improve**

Over half the parent carers were not involved in the RAS form. Parent/carers *must be involved* in the process and they must be informed what information they will need from professionals, such as teachers, health and any other professional or volunteer organisations that have contact with the family, to ensure that relevant information is included to support the application.

Children’s social workers and CWD teams need to listen to parents and children with a non-judgmental approach to help parents fill in the RAS questionnaire. They should look at all the relevant evidence and confirm with the family that the information gathered is correct and parents are happy with the forms that have been filled in before the end of the conversation with the family.

Give families enough time to complete the RAS questionnaire without feeling pressurised.

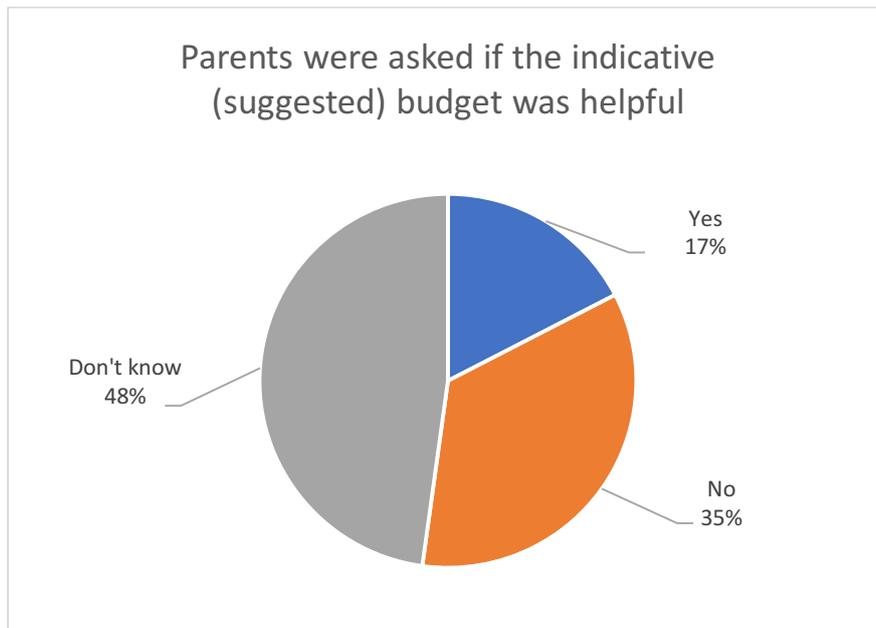
Review the RAS questionnaire so that the questions are relevant to all C&YP with SEND and so that they are clear and understandable questions; perhaps an easy read version should be available if parents or young people need it.

Parents would value receiving a communication to say the referral had been received, an indication of likely waiting times and a number to call if they have any queries /concerns

## Section B – Your budget

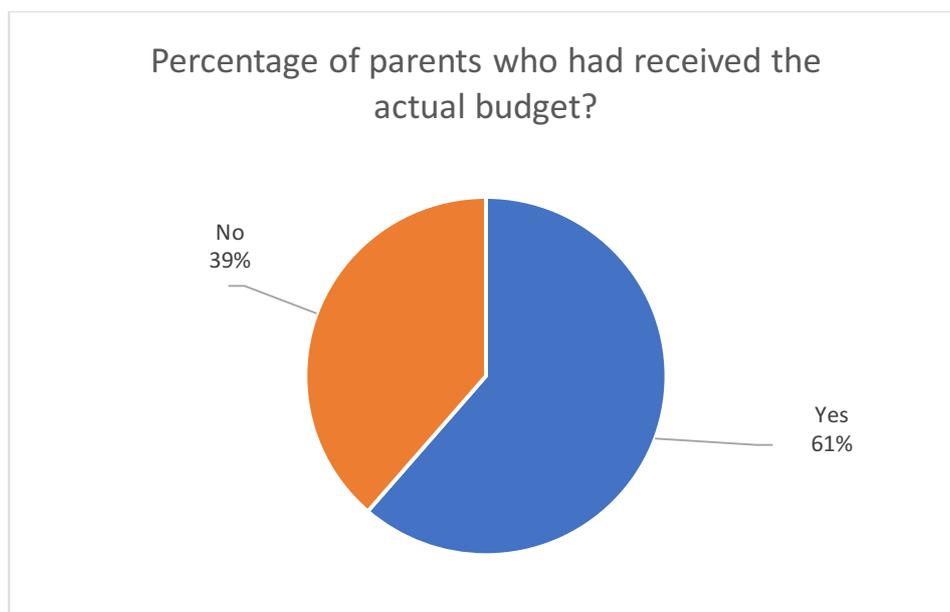
### Was the indicative (suggested) budget useful?

46 parent carers responded. 8 (17%) found the indicative budget useful, 16 (35%) did not and 22 (48%) did not know if the indicative budget was useful or not.



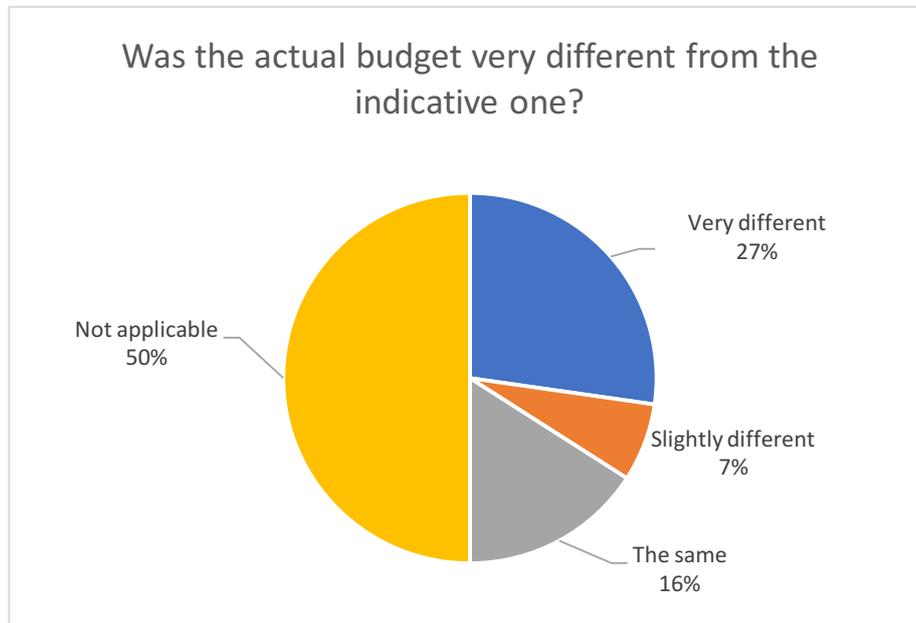
### Have you been given your actual budget?

44 parent carers responded to this question. At the time of the survey, 27 (61%) had received their actual budget while 17 (39%) had not.



### Was the actual budget very different from the indicative one?

44 parent carers responded to this question. 50% were unable to answer the question because they had not received an indicative budget or an actual budget.



### If you were unhappy with your budget did you appeal or complain? Were you successful in getting your budget changed?

20 (43%) respondents were unhappy with their budget and of those, 9 parent carers complained. This means that 45% of unhappy parents complained, although this amounts to 9% of all respondents who complained.

Of those 9 complaints, two thirds were successful in getting their budgets improved.

### Did you receive notification of your final budget in writing?

27 (52%) of parent carers had received their actual budget and of those, 14 (30%) had received notification in writing.

### Do you have a Short Breaks Contract from Norfolk County Council?

From 42 responses 23 (55%) had received a Short Breaks contract from NCC. The remaining 45% did not and there are many reasons for this. However, of the 27 that had a budget, 8 of these had not received a contract. 30% of parent carers who had a budget still had not received a contract.

### How to improve

Families need clear information regarding budgets and who to appeal or complain to, plus information on who to contact for help with both.

All staff involved with families accessing Short Breaks need to receive the same training and be able to provide the same information about the application forms, the allocation of budgets, the provision (specialist or universal) and the appeals/complaints procedure.

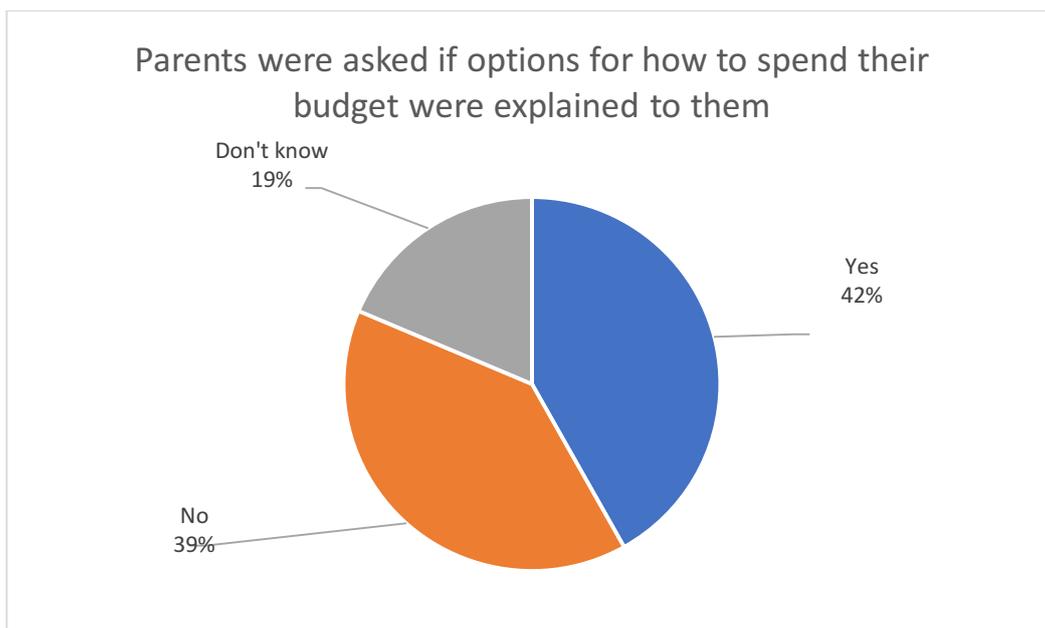
Once the budgets have been finalised and any appeals/complaints have been successfully dealt with, the delivery of contracts needs to improve.

Norfolk County Council might want to investigate a dispute resolution service to handle appeals/complaints with families in a sensitive and impartial way so relationships with families and children's social services can be rebuilt after any disagreements have arisen.

### Section C – Activities Available & Spending your budget.

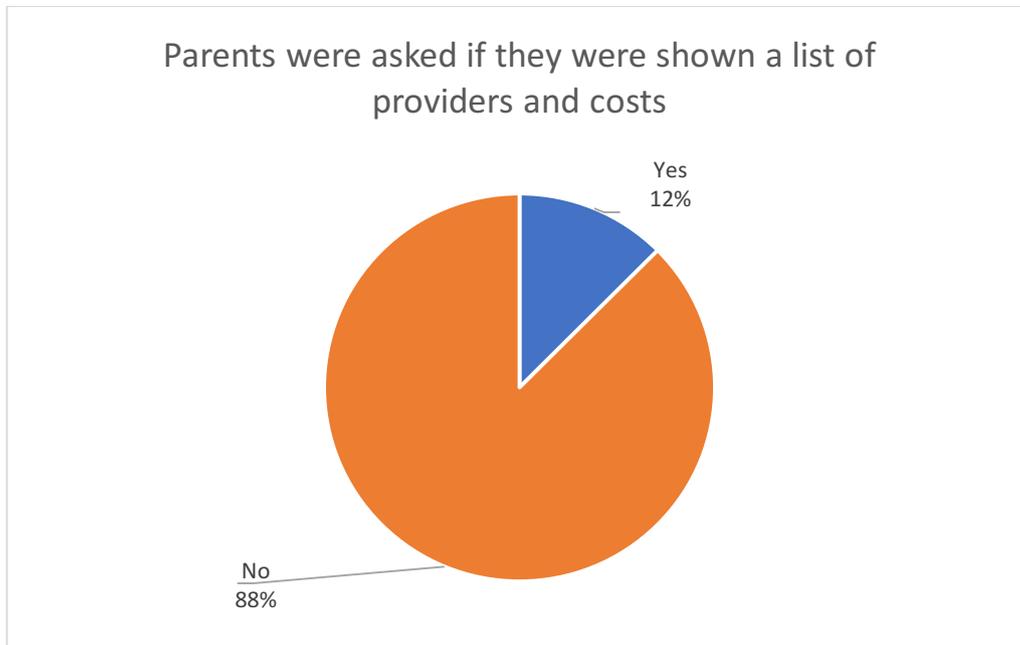
#### Were the options for how to spend your budget explained to you? (Providers, employing a personal assistant, specific activities, etc.)

43 parent carers responded to this question. 18 (42%) said that yes, the options had been explained to them, while 17 (39%) said no. 19% of parent carers did not know.



**Were you shown a list of providers and costs?**

40 parent carers responded to this question. 35 (88%) said that they were not shown a list of providers while only 5 (12%) said yes, they were shown a list.

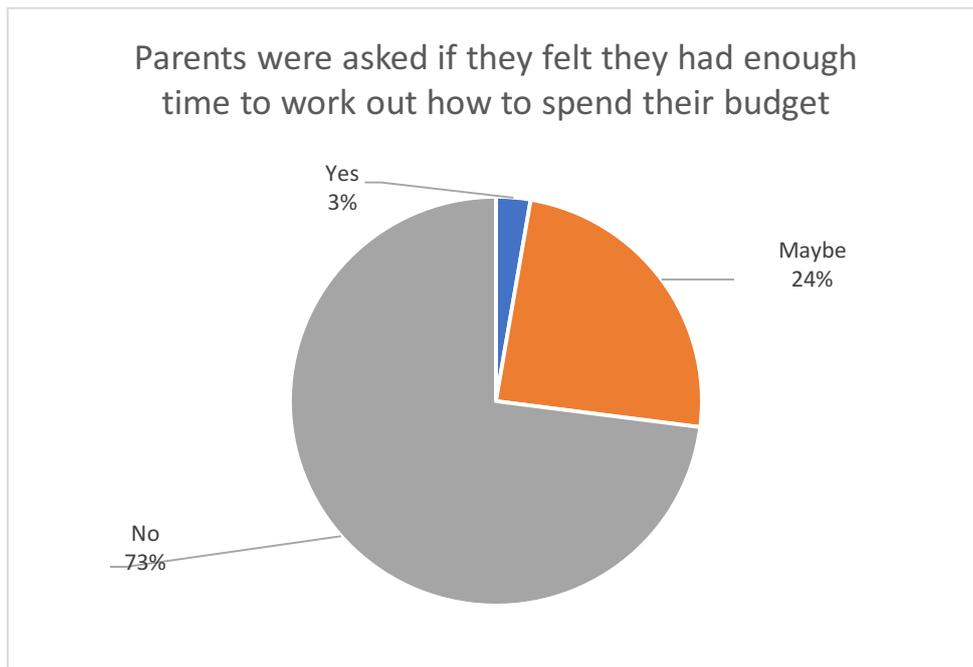


**Were you told what extras your budget would need to pay for if you are employing a personal assistant? (Mileage, Healthcare needs, training, insurance, sick pay, holiday, etc.)**

43 parent carers responded to this question. Only 4 (9%) said that they were told about the extras that the budget would need to pay for, while 24 (51%) were not told. Of the 15 that said it was not applicable, half of these did not have a budget.

**Did you feel you had enough time to work out how to spend your budget?**

37 parent carers responded to this question. Only 1 parent carer felt that they had enough time to work out how to spend their budget. 27 (73%) said that they felt they did not have enough time.



### Have you started using the Short Breaks Provision?

43 parent carers responded to this question. 34 (79%) said that their Short Break provision had started while 9 (21%) had not started using their provision.

See Appendix E for comments from those who have not started.

### How is everything working out?

32 parent carers responded to this question. 22% said that everything was good, 34% said everything was OK and 44% said everything was not good.

#### Everything is good

*"Hamlet centre is amazing, and I can't fault them is everything my child needs and more."*

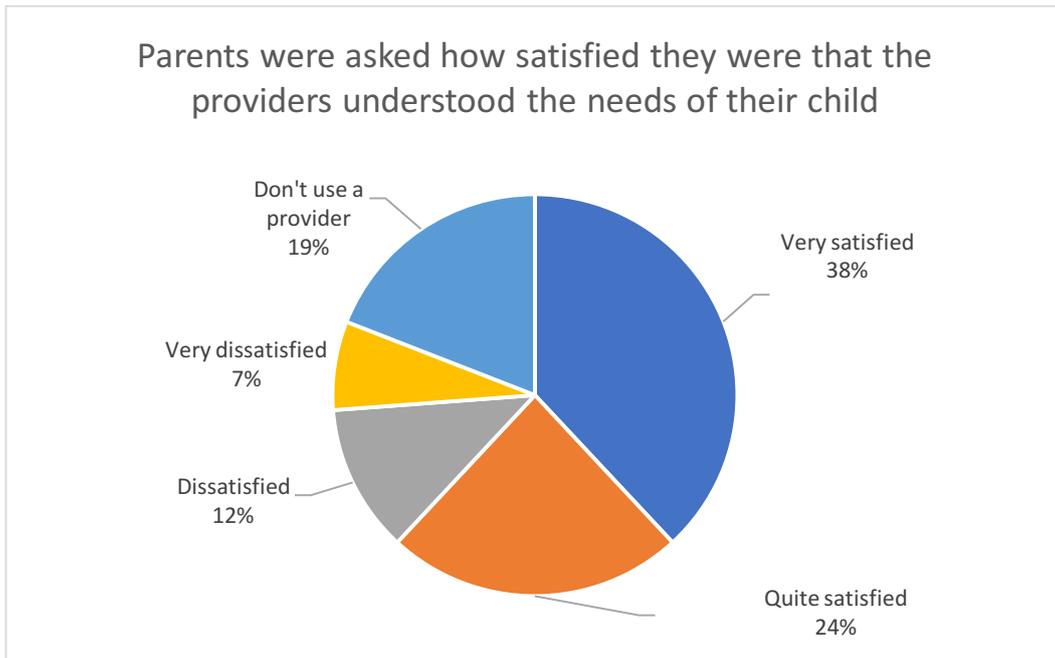
#### Everything is not good

*"Waiting to appeal as my overnight respite is going to be taken away even though it's taken my child a year to get use to going- a nightmare."*

Please refer to Appendix F for all the comments.

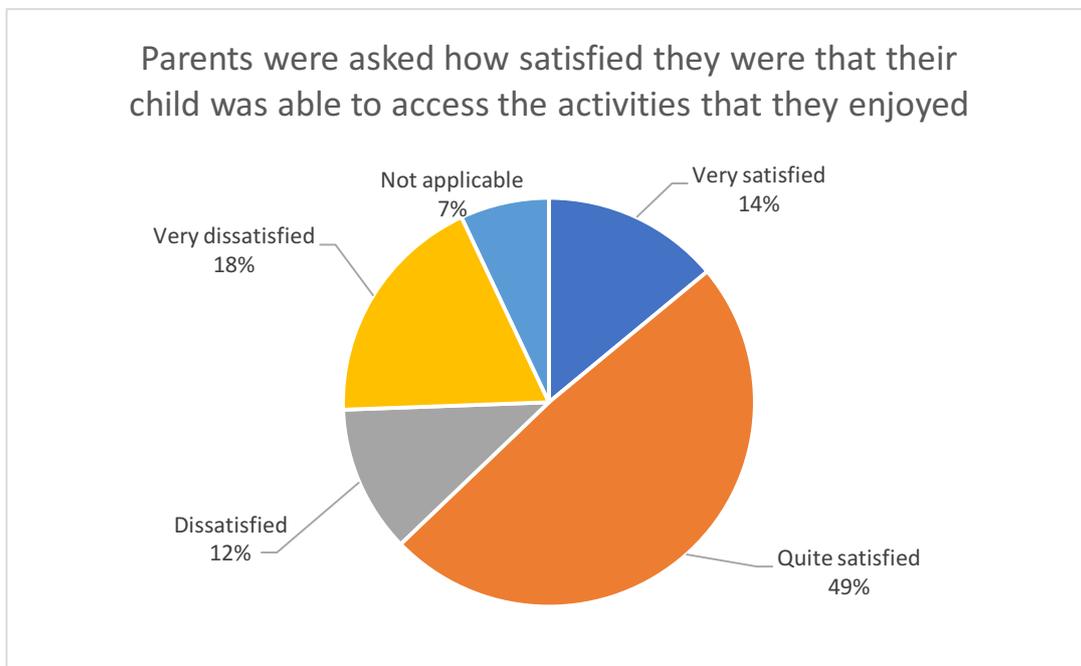
### How satisfied are you that your providers understand the needs of your child or young person?

42 parent carers responded to this question. 16 (38%) were very satisfied that the providers understood the needs of their child, 10 (24%) were quite satisfied, 8 (19%) were either dissatisfied or very dissatisfied.



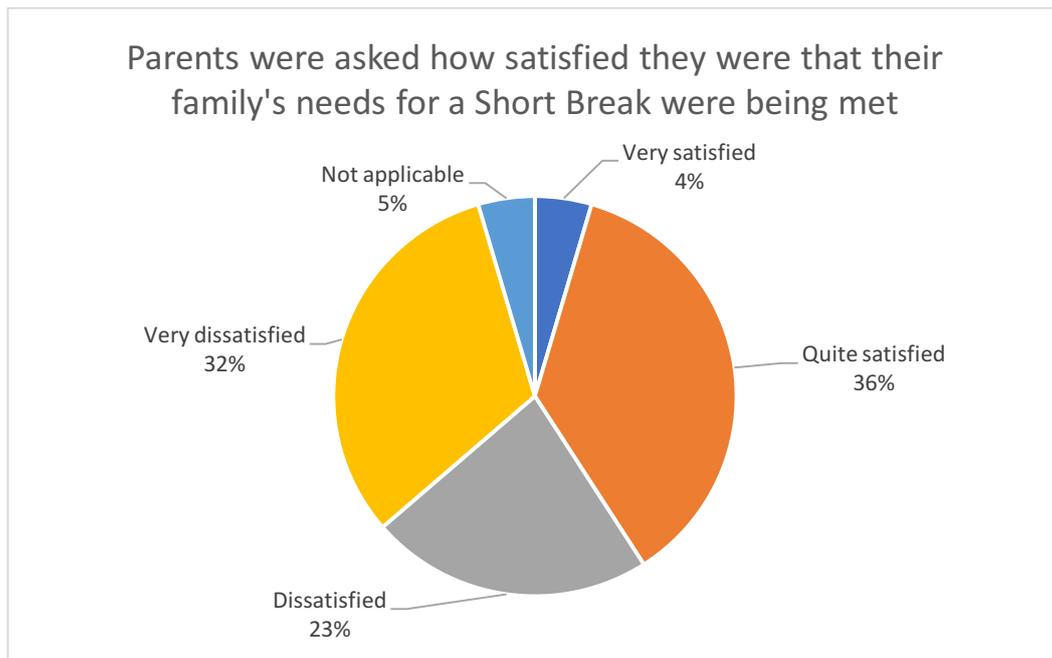
**How satisfied are you that your child or young person can access activities that they enjoy?**

42 parent carers responded to this question. 6 (14%) were very satisfied that their child or young person could access activities that they enjoyed, 21 (49%) were quite satisfied, 5 (12%) were either dissatisfied and 8 (18%) were very dissatisfied.



**How satisfied are you that your family's needs for a short break are being met?**

44 parent carers responded to this question. Two (4%) were very satisfied that their child or young person could access activities that they enjoyed, 16 (36%) were quite satisfied, 5 (23%) were dissatisfied and 8 (32%) were very dissatisfied.



**If you were dissatisfied or very dissatisfied, did you appeal or complain?**

27 (61%) parent carers from the 44 that responded to this question, were dissatisfied or very dissatisfied. Of these 11 (41%) had complained, 9 (33%) were considering complaining and 7 (26%) were not going to complain.

When asked if they knew who to complain to, 4 of the 16 said yes, while 12 (75%) said no, that they did not know how to make a complaint.

**Do you use any “universal services” e.g. local clubs and activities available to everyone?**

We had 44 parent carers respond to this question. Only 13 (30%) respondents said that they used universal services, while 31 (70%) said that they did not.

**How to improve**

Provide parents with more information about budgets and whether there are any hidden extras such as mileage, cancellation fees, etc.

Provide clear information on what they can spend their budgets on, whether it's personal assistants, activities, etc. Provide information on organisations that can help parents with information about employing a personal assistant.

Provide a list of specialist providers and a list or information about where to find universal services in their areas.

Provide parents with more information and contact details on who they can turn to if they have issues or concerns.

## Section D – Is there anything else you would like to tell us about the new Short Breaks system?

Here are some of the additional comments made by parent/carers. The full list of additional comments in Appendix G.

*“Our allocation is about a quarter of what it was which is very unfair as my son is unable to access universal services and we have challenging family circumstances. There needs to be a list of available opportunities and costs. Everyone including CWD team and providers were very confused and it was very rushed.”*

*“Not being able to use a family member because other people have abused the system is unfair. The massive charges for Musical Keys and The Hamlet Centre mean that he would only get a few sessions in an entire year - useless! Scope were excellent and used on a bi-weekly basis and now they have gone too.”*

*“I hope the system is thoroughly reviewed to make it work better in future years. More professional support is needed to explain the process and guide families through it.”*

*“I am a foster parent. I didn't know about budgets until I was told by a youth club worker. I then had a real battle to get social worker to agree to carry on funding youth club. I think that by not giving LAC children a budget is terrible. I was told it is because social services already pay for living cost that they will not pay for short breaks. It is not the child's fault they had been put into care system so why are they not able to have the same provisions as everyone else? PS when I spoke to a short breaks provider about personally funding some sessions, I was told that they have a contract with social services so anyone self-funding will only get places if social service-funded children don't want them. This isn't fair!”*

### General results from the survey

It is clear that most parents who gave a view would welcome greater transparency and more information about:

- the criteria for allocating Short Breaks
- how to apply for Short Breaks
- where to find support and advice about the application
- how budgets work and how they can be used
- what provision is available (both specialist and through universal services) and how to access it
- time constraints and how reviews are handled
- what to do if they are not satisfied with the service or result of their application.

It is also clear that parents feel that the existing RAS is more suitable for some kinds of SEN and/or disability than others. They would like to see a RAS that covers the needs of all children and young people who may be eligible for Short Breaks.

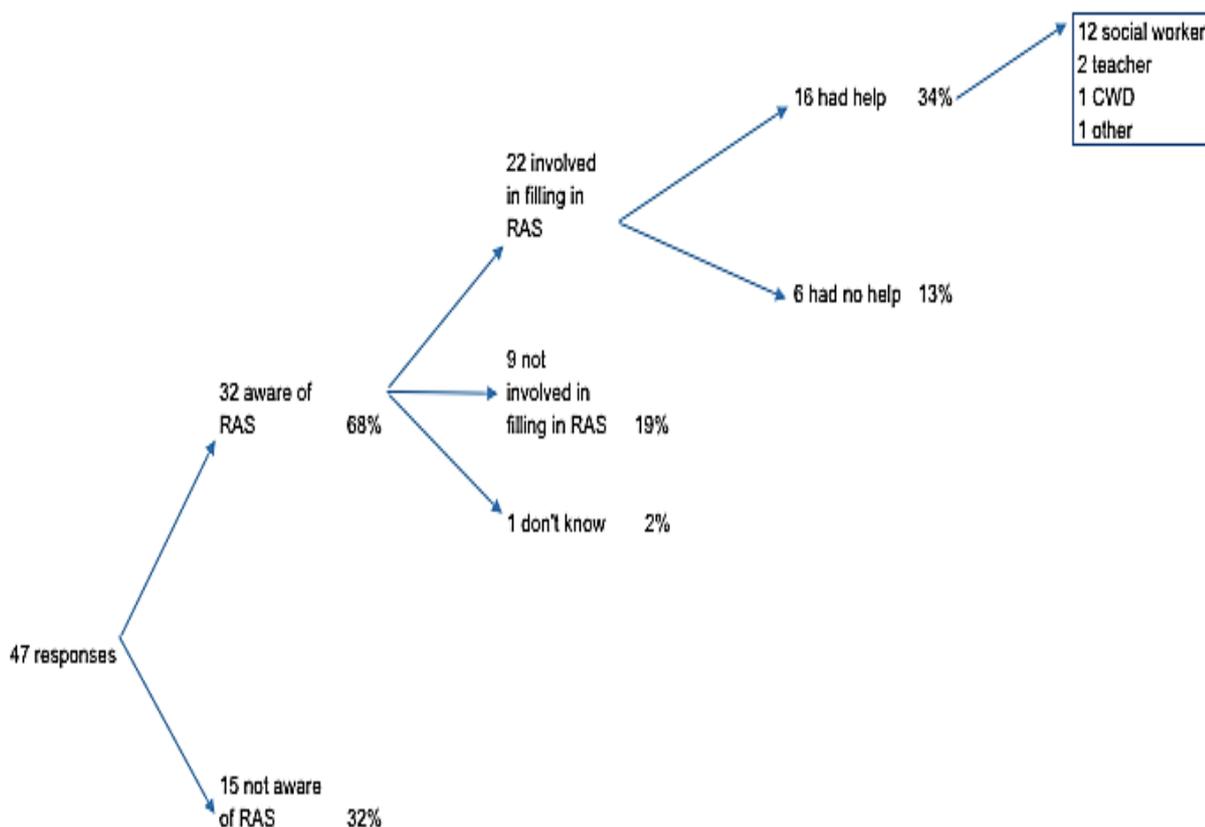
Finally, Short Breaks cannot be viewed in isolation. The situation of the child or young person's immediate family – financially, socially, geographically and in other ways – is often very relevant to what kind of Short Break provision will best support the child or young person and enable the family to continue to be a key factor in his or her support. It is also important that the family is made aware of all the kinds of support to which they are entitled, such as via carer assessments, support groups and benefits.

When a system that is meant to support children and young people with SEND results in increased stress for families already living with additional stresses, changes need to be made. As always, Family Voice would recommend listening to parents themselves about how to provide the best service possible.

## Appendices

### Full comments by parents

#### Appendix A – Involvement of parent carers in completing the RAS Questionnaire



#### Appendix B – What did you think of the questions in the RAS questionnaire?

- They were difficult to answer for my child
- Quite ambiguous particularly between some and lots of support.
- They didn't suit my child's needs
- I found some things a bit hard to quantify
- They only took account of the child not the whole family
- it felt like a money exercise but necessary I suppose. I worried about the help we currently got would change.
- awful, some misleading, even professional who looked at it totally got the wrong idea from the staying safe in the community question
- At the time that I completed it I was unaware that it would be the basis for my child's short breaks budget. We later appealed the decision which resulted in a higher score and bigger budget. Some questions were not relevant and not explained enough
- The questions are carefully worded to ensure that many more people are excluded from having support to ensure social services saves money

- Stupid, hardly anyone will qualify
- Didn't like it, not all the questions fit
- Not good
- Awful. Very woolly, still very focused toward physical difficulties even though I was told it was supposed to make it easier for children with Autism and other hidden disabilities to get support.
- Seems to score you less the more you do for your child
- Some of the questions were difficult to answer
- Very directed questions, not good and not designed for my children with ASD or many other issues
- I think there are significant issues with some of the questions particularly those where children with autism are marked as no support needed due to the efforts of parents to look after them well. I don't feel that support from extended family should be used as a reason not to award respite. The survey was not reflective of my child's needs (he has very complex needs and came out in the low-level needs category) and not fit for purpose. One of our providers asked for 2:1 support for him to be able to take him out!
- Complicated, I felt that my child fitted more than one answer
- The application process is a joke we were refused even with support for asd helping hands got the refusal 2 days before this year's family voice conference, so I attended short breaks work shop and then had speed date with member of short breaks team and questioned it 2 weeks later we are awarded short breaks many parents would not question the refusal.

### **Appendix C – How long did you have to wait to hear whether your application had been successful?**

#### **Told straight away**

- Social worker rang it in straight away
- Social worker told us what we would get on day, we told her we would take it to panel as not enough if respite included
- They told me then and there at Face to face meeting that we were awarded a £4.000 budget, which is great, but it is cut, we cannot afford any of the specialist provision such as musical keys as that would take over half budget, then we must allow for overnights at brownie camp and weekly attendance at brownies, and every other Sunday.

#### **Took a long time**

- Not sure but it took long enough that we missed booking any Feb half term sessions. Further delays were caused by appealing the score, so we missed booking Easter and Whitsun holiday sessions too. The first session my child has been able to book this year is in last week of July.

#### **Still Not Heard**

- Our contract was up for review in the middle of February but we received no information until I called a couple of days later. We are now doing a full renewal and despite all the evidence having to be submitted by 2 June (contract expires 2 August) as at 5 July our application has still not been "allocated" to a worker. Given the length of time to get things set up which resulted in us not having things in place for the April Easter holidays following review, I am now really worried about the summer holidays.
- Still waiting for acknowledgement of receipt of application form - 6 weeks so far

## Appendix D – Could you tell us what was good about your family’s experience of the RAS Questionnaire process and what could be improved?

- More boxes some questions overlap
- We managed to increase our child's funding to a higher level
- The fact that, after objections from us as a family, we were able to revisit the survey.
- Social worker was rushed and didn't have sufficient time to do a thorough assessment
- Letting us know sooner the outcome as we felt we could no longer access support because we
- did not know if we could still access our child’s allocated money during that time.
- It would have been better if we hadn't had to do it in March and again just now for August (which means we may miss some summer bookings).
- It's not always black and white and as easy as health professional think it is
- Not to be given wrong info, were told that all people with autism got 0 on one question, my son got highest
- If I had not of gone to family voice conference I wouldn't of got short breaks
- not enough clarity in questions and the answer you might need to give was often not in the answer
- The questions are ridiculous
- I was given a total score as judged by them based on evidence from last year which clearly did not reflect what we currently receive so it appeared that they were trying to cut my provision by about 75%. It was only when I queried this that it was suggested I fill out the questionnaire myself and see what result I got.
- Opportunity to see online and discuss with CWD team. Felt like I gathered lots of evidence that was mostly ignored, probably because the questions are so ambiguous
- The CWD team completed the RAS and presented me with the score. I do think it would have been better to complete this with me, after all, the lady at the end of the telephone has never met my child
- I filled in some paper work which was then taken up by a SW from child with disability team. The process seems a mystery. How do they work it out?
- Parents be given it ahead of meeting with social worker
- I am really disgusted with children social services as going through the RAG questionnaire our son could qualify for short breaks but no one at children services from EHCP coordinators and Register for disabled children have bothered to tell us about this.
- Nothing good or bad. Same as last years.
- Good as we have some short breaks but have since looked at the RAS questionnaire and it looks like the person that completed it for us (that we weren't aware of) has filled it in incorrectly.
- Letting us know sooner the outcome as we felt we could no longer access support because we did not know if we could still access his allocated money during that time.
- Social worker was rushed and didn't have sufficient time to do a thorough assessment
- I found it very confusing when we were being told we had a RAS score and budget but yet were not on the new scheme (which was based on hours). I also had no idea how the RAS score was compiled. I had to do my own rough calculations to try and work out how if compared to the hours budget we had before. Luckily it was much more favourable as the old system capped us at 150 hours as we have no social worker. Having no "social worker cap" is definitely a good idea!
- clearer questions, and I'm not sure how the disappointment could have been avoided when we worked out what package we were receiving, to what we go on to get
- It is good that it helps a family to focus on what the purpose of short breaks is and make sure they are accessing the best options for their child and themselves. It is also good to have an awareness of the cost of provision.

- The new process seems to have been brought in too quickly with very little explanation and professional support. Our experience was a significant drop in provision which we challenged and saw an increase that we are happy with but not back to the level of previous years, despite the fact that my child's needs are increasing as he gets older. The whole process was emotionally difficult and time consuming. Many parents / carers would not be strong enough to question their outcome. It felt like another example of having to make a bit of a fuss just to receive what is needed and if you don't have the ability to do this you lose out. This is not equality.
- I never completed a questionnaire, my renewal came with a score and some forms to fill in re why I and my daughter need short breaks.
- We were involved & s/w listened to our views.
- For kids who need 1:1 care the questions about being out and about were irrelevant unless the 1:1 carer was there
- My daughter's nights may not have been reduced but the thought of not having a full weekend to spend with my 3 other SN children ie cinema (over 18s) museums and a weekend away makes me feel I am failing them. They ask for so little. As for no respite over school holidays I will break!
- It was clearly explained online
- We managed to increase our child's funding to a higher level
- The fact that, after objections from us as a family, we were able to revisit the survey.

#### **Appendix E – If you've not started using Short Breaks, can you tell us why not?**

- My child cannot leave the house, so a short break budget isn't much use when they can't go anywhere and use the budget.
- Because I was told categorically the money could not be used for a personal assistant!
- They said our child doesn't meet the criteria, our child has Autism.
- We are giving ours all to our deaf charity

#### **Appendix F – Have you started using the Short Breaks provision? How is everything working out?**

##### **Everything is GOOD**

- Hamlet centre is amazing, and I can't fault them is everything my child needs and more.
- Very well - a PA is in place and we do have short breaks from one provider too.
- working well, giving me more time to get stuff done that wouldn't happen with my children at home.
- My child is attending the same provision before, with an increase of 3 sessions. There was a worry on my part that as my renewal was in July I therefore be one of the last to book for the summer holidays, I had the pick of what was left so not ideal. In June already, I could not book a December date at the provision my child goes to as they were already fully booked, I therefore think it is luck of the draw where your renewal is as to what you can book! I think my child's budget was worked out by how many sessions my child could book at the provision not what she was entitled to. If I had done the questionnaire which I was unaware of at the time I'm quite confident my child would be entitled to a much higher

budget, the problem is there isn't enough provision or alternatives for those with complex health needs

### Everything is OK

- Hopefully ok, we are having an extension, so that we will only need to renew in 18 months, so shouldn't have the summer holiday booking problem, where we can't book until it is all finalised. Now we have our contract, but the Hamlet Centre haven't received theirs yet, so we can't yet book
- I got offered more than was first said, happy with amount but had no say in where money got spent and still trying to swap some services
- The provision we have is good, but we have had to fund extra privately despite being on a very low income. My child was devastated to lose the extra hours.
- We are only using services we have always used as we do not know what else is available
- Ok but future uncertain
- Everything is ok
- Our budget is less but we are grateful for any support. Our child will get to do an activity, but the support will be shorter not over the whole year. No more pa. It has encouraged my child to choose a hobby that is maybe something they would not ordinarily choose.
- I get what I asked for but was unaware that overnight respite would be included in the budget
- ok but it depends what happens with residential short breaks at squirrels now that Norfolk county Council part funds it
- Ok - a lot of repetitive unnecessary form filling as providers are requesting their own versions of the All about me. Very rushed and hurried to set up in the summer and not able to access full provision because of this. One provider failed to do a meet and greet which was incredibly worrying for us.
- Ok - not brilliant but ok

### Everything is NOT GOOD

- No, the budget doesn't give me break or time to spend with my child.
- Not too well - my child did not like the youth club provision, but the provider took 3 month's cancellation fee wiping out my budget. Would prefer a personal budget that I can choose to use myself and control myself.
- It took us 3 months to get a personal assistant up and running as the Council did not notify Equal Lives that we were having one. Also, a DBS check was required despite the assistant working with our child at his school. The contract with one of the listed providers was not organised by the Council in time for the Easter holidays and so our short breaks provision was basically halved as a result. We are not able to carry that budget forward or use it in another way. The whole process of vetting everything reduced me to tears as I kept being told things by the A2S team that were incorrect (e.g. I needed to call Equal Lives to get a carer set up, but they were not allowed to without a referral). I am optimistic that in the longer term the new system will be a lot better for us, but the short-term pain is high. Now, as in the past, I feel I need a "short break" due to the stress and amount of time it has taken to negotiate the system. I also asked for a list of what could be paid for out of the budget and was told there wasn't one and, so I am still not clear whether we are using it as we could.
- I said it was about cost cutting they said it wasn't, so ok you try and make the best of it, they seriously hassled me to make decisions with little time and information, I didn't know about the hidden costs which then mean less physical hours of care, then the petrol

allowance , we didn't have a choice of what to pay as they were a scope member of staff previously, there needs to be a rurality discretion built into this , we will probably spend about £500 plus on mileage a year because of where we live, and our child is too big really for planet zoom and you can't stay in there for 4 hours NCC suggestion. I still have unanswered questions from NCC all the stress they put us through with this in January Feb and March, then nothing no paperwork. and the conversation regarding training for someone to do medical care, I felt bullied, I kept saying x needs training as is going away with my child NCC very forcefully why don't (just do the whole trip?) doesn't want to etc took weeks to sort out the funding for the training to be put in place, difficult phone calls

- We have much less provision than before because of the way it is managed.
- Not great, wish we had known about other options
- My child is frustrated and upset at having to wait longer for provisions
- Provider after 4 sessions has refused to work for us due to an error of theirs which we questioned
- Frequently I get more current information from Short Breaks team than social workers
- Does not start until the summer holidays
- Very badly
- Still waiting for a budget
- It's been about 5 weeks since I submitted a pile of evidence with my questionnaire and form and im I'm waiting for a social worker to be allocated and do an assessment, so I was not able to answer all your questions.

## Appendix G – Other comments

### Section D – Is there anything else you would like to tell us about the new Short Breaks system?

- It does seem silly to have tried to change everyone over in March and then we needed to renew at the normal time as well, it was unnecessarily complicated. We could have just changed to the budget system when we needed to renew. Also, each time, I have chased up what's happened with the Short Breaks budget, whoever I've spoken to on each occasion has been very helpful but I shouldn't have to be chasing up our allocation.
- It needs look it and social workers need to know the system
- A con in getting rid of certain children out of the system, yet again single parents get everything yet a couple struggling get zero. System is all wrong, worst system in 14 years of my son using short breaks. Our allocation is about a quarter of what it was which is very unfair as my son is unable to access universal services and we have challenging family circumstances. There needs to be a list of available opportunities and costs. Everyone including CWD team and providers were very confused and it was very rushed.
- It was a very rushed process for us, rushed by CWD team, and rather disorganised. Lack of consistency depending on the persons I spoke to. Having said that, the outcome has been a good one and the short breaks that my son and we as a family do receive, are working well, mainly because I maximised the budget by employing a PA and not relying solely on the providers. Having seen the costs of the providers now (this was not available to me at the time), I might look at turning to a PA for all provision as this is the most cost efficient.
- It might help if I had actually known what my son could be provided with and the SW also knew what was available and that access arrangements were made for his disability so he could make use of the budget.
- We would like to do short breaks, need more information.
- Our children's money has been cut considerably so that means they will not be able to access anywhere near as much as they did before

- Families need a clearer breakdown of costs and a list of all costs and providers up front. We feel the decision to offer short breaks on a cost basis is problematic because our linked families placement is due to end and we can't find another. We have been told a similar package at residential care would cost double, therefore halving the number of sessions we would get. The social worker has offered to go to panel but it's a long slow drawn out process with a lot of uncertainty.
- Yes why aren't more parents being told about this?
- Not being able to use a family member because other people have abused the system is unfair. The massive charges for Musical Keys and The Hamlet Centre mean that he would only get a few sessions in an entire year - useless! Scope were excellent and used on a bi-weekly basis and now they have gone too.
- Think they have been really sneaky and cut the budget down and not even contacted us to fill in the RAS questionnaire properly.
- The cutting of services in our area is being halved and no thought given to the families who are being stretched more and more. At the moment a group of parents are in the middle of contacting MP and going to press.
- Families are not getting what they need. It's all about saving money as usual.
- Old system ended 25-3-17, our named social worker gave us a list of 6 choices and price list 3-4-17. Leading lives started 13-5-17, ended 31-5-17. Our social worker has not contacted us or replied to our 3 emails.
- We can't use providers as they are too expensive for my [child's] level of care, and it's sad that they took the short breaks away from the most vulnerable to make it go further with no extra money, it's too thin a service, and it was done in far too rushed a way. and I dread having to renew next year already as we have to work out what we've spent etc, because if you don't spend it, it won't be there next year.
- I hope the system is thoroughly reviewed to make it work better in future years. More professional support is needed to explain the process and guide families through it.
- I don't think it is very clear what you are entitled to and why it varies so wildly for different children. Some basic understanding of how it is calculated would be helpful. It just feels a bit luck of the draw, I certainly didn't get any help and never saw a questionnaire. I was very panicked by the summer holidays approaching and having not booked anything I didn't want any delay, so therefore never questioned what I had been given.
- No options available to spend the budget. Respite needed out of home.
- it needs to change to be more parent/young person friendly and short breaks needs to be available to more people
- Now that NCC are contributing to squirrels, some people are having to lose home care as the residential cost is now included in their total budget where it wasn't before. the needs of the family have not changed however.
- Yes The new system for use of Squirrels is unfit for purpose, we need a break from 24hr caring and like to go away for weekends when child is in, but that is going to change because they are going to close on Sundays, so we would have to get back on Saturday night.
- The other main one for us is that we are heavily involved in [a carnival] and with the new system of squirrels only opening 1 week in the summer holidays we are going to have to stop doing a lot of the work we do.
- For others it is different but everybody agrees that how they can fit as they say 25 children into 1 week during school holidays.
- Also with the unit only open 29 weeks of the year, the staff would change and possibly agency used so there is no continuity of care that our child requires.
- The cuts are so unfair to parents with school age children, if they take their children out of school for a SHORT break they will be fined by the LEA is this fair. Personally my [children]

- have not had a holiday for 7 years due to problems with [one of them]. We have adopted [several children, some with complex needs] how much money have we saved this country
- Most of the suggested providers are not suitable for my child's needs or don't fit in with our free time or are too far away to be viable
  - We were only given list of providers after asking many times and info given was minimal. The system has not been given enough thought before it was imposed. The RAS questionnaire is very badly put together to gain an unrealistic view of the child and family's needs. Information given is sketchy and incomplete. A total farce and not designed for purpose.
  - There is a lot of positive in terms of the kinds of activities actually on offer and the "outcomes" focus. However, the whole application process was a nightmare and the attention to detail from some providers who keep phoning to ask endless questions has been tiring and stressful. We have not received a break as the whole process to set it up has been a incredibly stressful and unjust and sometimes left us in tears having to fight to have our son's needs properly identified and understood
  - I am a foster parent. I didn't know about budgets until I was told by a youth club worker. I then had a real battle to get social worker to agree to carry on funding youth club. I think that by not giving LAC children a budget is terrible. I was told it is because social services already pay for living cost that they will not pay for short breaks. It is not the child's fault they had been put into care system so why are they not able to have the same provisions as everyone else? PS when I spoke to a short breaks provider about personally funding some sessions, I was told that they have a contract with social services so anyone self-funding will only get places if social service-funded children don't want them. This isn't fair!