



## Short Break Service - Parent/Carer Survey 2019

### About the Survey

We are interested in the views of parent/carers of children with special educational needs and/or disabilities who have used a short break service from **April 2018 onwards**.

The survey will take about **15 minutes** to complete.

Please only complete this questionnaire if you are a parent/carer of a child/children with special educational needs and/or disabilities who have used a short break service within the time period above. The views of children and young people and providers of short break services are being gathered separately. All the feedback including the results of the previous Lancashire Break Time consultation will be used to make a proposal for the future delivery of short break services across Lancashire.

Please note the use of the term child or children in the questionnaire refers to all young people up to 18 years of age.

Please submit your completed questionnaire by **21 October 2019**.

If you have any queries about completing the questionnaire or if you would prefer to complete the questionnaire on a paper copy please call 01772 532509 or email [Find@lancashire.gov.uk](mailto:Find@lancashire.gov.uk)

Thank you in advance for your time.

### About the children you care for

#### **How many children in your household have a special educational need and/or disability?**

*Please type the number of children in each age group*

under 5 years old	24
5-10 years old	145
11-16 years old	158
17-18 years old	58

**For each child in your family with a special educational need and/or disability, please can you tell us their primary need?**

*Please select as many as apply for each child*

	Child 1	Child 2	Child 3	Child 4	Child 5	Child 6
Autistic spectrum disorder (ASD)	186	38	13	1	1	1
Speech, language and communication needs (SLCN)	180	16	6	2	0	0
Specific learning difficulties (SpLD) eg dyslexia, dyscalculia, dyspraxia 71	71	11	3	1	1	1
Hearing impairment (HI)	32	6	4	1	1	0
Visual impairment (VI)	51	12	2	0	0	1
Physical disability (PD)	82	7	4	0	0	1
Learning disability/difficulties that includes mild, moderate, severe and profound and multiple learning difficulties (LD)	226	28	8	2	2	0
Social, emotional and mental health needs (SEMH)	114	21	5	0	1	0
Other	32	4	1	0	0	0

If you have selected other, please type details in the box

- Behaviour issues
- All round care - have to watch my son at all times because he will hurt himself or break something. No sense of fear or danger.
- Chromosome disorder ADHD
- Sleep disorder
- Also has attached and sensory processing issues SPD ADHD
- Sensory processing Ectodermal dysplasia
- Child 1 is aged 10 has severe Autism and severe ADHD and other multiple complex needs (child 2 is 15 was diagnosed with global developmental delays when aged 5 now hes 15 he's been Re assessed and as
- Sensory processing disorder ADHD
- Fragile X
- Type 1 Diabetes Congenital hyperinsulinism
- Dravet Syndrome with associated ASD and severe learning disabilities and challenging behaviour. Rare genetic condition - Syngap 1 Syndrome
- Brain damaged Adhd
- Sensory Processing Disorder and Visual Processing disorder Child 3 also had adhd as well as asd and mild learning disabilities Epilepsy
- Sensory Attachment Processing, Attachment Disorder sensory disorder, motor skills problems
- ADHD
- Sensory processing difficulties Angelman Syndrome
- Visual Processing and Auditory Processing Disorder, awaiting outcome of ASD assessment adhd
- Attachment disorder and adhd
- Kai sees a psychiatrist Dr Ahmad at Elcas Burnley hospital for check ups PDA
- Epilepsy

- ASD traits on the pathway ADHD
- ADHD
- Adhd Adhd
- Downs syndrome Sensory processing ADHD, SPD and APD
- medical needs ADHD
- he has down syndrome Epilepsy.
- Adhd and odd EA type II
- ADHD
- ADHD Bowel issues
- Fragile X syndrome
- FASD, attachment disorder, and possible ADHD
- Pithopkin dease
- ADHD
- They are all primary needs.
- Adhd
- Personal care whole of body.
- One has significant medical issues, namely one called neutropenia meaning he does not have much of an immune system

**Q5 What education setting does your child/children attend?**

*Please select as many as apply for each child*

	Child 1	Child 2	Child 3	Child 4	Child 6	Child 6
Mainstream nursery/pre school	12	3	4	1	1	1
Special nursery/special pre-school	9	3	0	0	0	0
Home educated	2	0	0	0	0	1
Mainstream school	47	24	10	2	0	1
Special school	210	27	5	0	0	1
Mainstream college	15	2	2	0	1	0
Specialist college	21	1	1	0	0	0
Apprenticeship/internship/training	1	0	0	0	0	1
In employment/voluntary work	1	0	0	0	1	0
Alternative provision/short stay provision	2	0	0	1	0	0
Not in education, employment or training	3	0	0	0	1	0
Other	4	1	1	1	0	0

If you have selected other, please type details in the box

- Private independent funded by his ehcp Awaiting placement at special needs school EOTAS
- Currently awaiting transfer to special school
- both in PRU until special schools and EHCPs agreed

- Child 1 goes holly grove specialist needs school primary in burnley and child 2 goes to all Saints Catholic High School In Rawtenstall
- Child 2 been waiting 18 months for assistance to have an ehcp before he can attend special school. Hospice overnight every 6 weeks
- Mainstream Part Time currently searching fro right Special School following EHC Plan Seeking personal budget for education at home
- Anxiety based school refusal

**Q Which of the following plans does your child/children receive support through?**

*Please select as many as apply for each child*

	Child 1	Child 2	Child 3	Child 4	Child 6	Child 6
Special Educational Needs (SEN) support plan	112	17	8	1	0	1
Education, Health and Care Plan (EHCP)	259	33	7	0	0	1
Common assessment framework (CAF)/Team Around the Family (TAF) support plan	54	13	3	1	1	1
Moving and Handling Plan	27	3	0	0	0	1
Health Care Plan	34	8	1	0	0	1
Post-Adoption Support Plan or Special Guardianship Support Plan	8	3	0	0	0	1
Child in Need Plan (CiN)	52	4	1	0	0	1
Child Protection Plan	1	0	0	0	0	1
Child Looked After (CLA) Care Plan	11	5	3	0	0	1
Leaving Care Pathway Plan	2	1	1	0	0	1
Currently undergoing an assessment (Education, Health and Care Needs assessment)	8	6	3	0	0	1
Currently undergoing an assessment (CAF assessment, Child and Family social care assessment, Early Help assessment)	0	2	0	0	0	1
My child does not have a support p	12	3	2	0	0	1
Don't know	2	0	0	0	0	0
Other	4	0	0	0	0	0

If you have selected other, please type details in the box

- child 1 has EHCP finalising a school
- Child 1 is u see going a parent carers assessment for a assessment tog Needs has a Ehcp in school child 2 is known to his school's Senco is awaiting Re diagnosis from global developmental d
- Behaviour support plan Behaviour Management Plan
- We used to have a social worker but she hasn't been to see Kai in along time. I used to get restbite but our pa has finished and struggling to find another.
- He receives support from the college he attends.
- Still fighting to get my son the support he needs 4 years and I will not give up Got an appointment to see someone
- Just about to start an EHCP assessment

### Use of short break services

**How many children with a special educational need and/or disability in your family have attended a short break service?** *Please type the number of children in each age group*

under 5 years old	19
5-10 years old	123
11-16 years old	134
17-18 years old	50
Have not attended short break service	0

**Which of the following short break services have you and/or your family used over the last 12 months?**

*Please select all that apply*

- 82 Lancashire Break Time after school clubs
- 79 Lancashire Break Time weekend clubs
- 48 Other after school clubs
- 17 Other weekend clubs
- 165 Lancashire Break Time holiday clubs
- 33 Lancashire Break Time evening clubs
- 39 Other holiday clubs
- 12 Other evening clubs
- 38 Home based or community short breaks funded through direct payments
- 6 Day care support as part of an adult social care support package
- 13 Home based or community short breaks commissioned from an agency
- 4 Day care support at a specialist centre (for example, Big Blue Door)
- 3 Short breaks with foster carers
- 36 Overnight short break at a short break/respice unit
- 4 Short breaks as a whole family
- 4 Overnight short break in the family home
- 7 Short breaks provided by a hospice
- 12 Don't know
- 16 Other

If you have selected other, please type details in the box:

- We pay from our own money for after school at a nursery 5 nights a week and during school holidays, but they are not a specialist setting and struggle to cope with his behaviour. Without t
- None as I was told my son could not receive any of this sort of support because he was going through
- assessment for ASD.
- None didn't know he could
- After moving area have not at ended any short breaks as yet
- None
- None
- Not used any
- Didn't use as Wasnt aware of service
- Nothing accessed due to nothing suitable available
- Charity holiday
- we have been offered none. prior 18 months we access lancashire break time but they are too
- complex to handle. i need respite from my children
- We are currently u see going a parent carers assessment and are hoping to get short breaks and
- respite care for our 10 almost 11 Yr old son soon
- None
- I don't get a short break for my daughter
- None as there is nothing available for his age!!! He went to barnardos once in fleetwood before it was pulled
- 4 night outdoor trip with Barnardos which I think was funded through lancs break time service but not 100%
- Have not been made aware there was any help so not used this provision
- None due to not being able to care for his medical needs
- None as yet - diagnosis only came earlier this year
- None
- Break Time Final
- None
- None I didn't know about this
- Action for ASD
- None
- I used to get 5hrs restbite once wk but our pa finished in July this year. I'm a single mum carer to my
- son I get no support now
- Non
- unable to find any after school clubs or holiday clubs to accept my son with his complex needs
- We don't really need this service, but I know how important it is for other families.
- Stay over at school
- I wasn't aware that these were available to us.
- Never used any of the service ,
- Blackpool football club

- Fleetwood football club pan ability football and Blackpool football club community trust pan ability football
- Play inclusion Project
- We have applied and registered but told there is no space, also because we get direct payments we have to pay £14.50 per hour which is almost equivalent to 2 hours we pay for the PA. Despit
- Having recently moved into the area I am not sure what the groups come under. We have used the following , Picaddilly services, unique kids, moro,s sat club, Awaiting results of social car
- We haven't used any yet but we were hoping to access a holiday club.
- My children used to attend an after school lancashire break time club once a week but council cut funding and sold the property club was ran from. Leaving them isolated through the week
- wave supported lives
- I've not yet used the service myself but know it's a lifeline to those who care for children 24/7
- We were hoping to use the big blue door so I could return to work, we have had to postpone that idea until we have some clarification on funding
- Nothing suitable

### **What are your main reasons for using a short break service?**

*Please select up to three things from the list below*

99 'Recharge my batteries'/'me time'

54 Catch up on rest/sleep

97 Undertake family and household tasks (for example, attend appointments, shopping, cleaning)

74 Spend time with my other children

130 Help me to cope with the demands of caring for my child/children with a special education need and/or disability

68 Help me to meet the needs of other children in my family

5 Allow me to undertake training/education

5 Allow me to pursue a leisure activity or hobby

132 For the child/children to socialise away from their family (for example, spending time with their friends)

52 Enable me to go to work (childcare)

23 Other

If you have selected other, please type details in the box:

- See previous answer
- I've not send him yet
- Unaware we could have access to this provison
- Don't use one
- My son is unable to access most holiday clubs due to his additional needs. His needs mean he has very few friends in school, the interaction with other children has had a significant impact
- Not used any
- To survive family life
- Allows me to spend more time with my mum in London
- These are what I would like to use short breaks for if I were to access any
- Also so my daughter can spend time with friends from school
- Children's self esteem and social skills
- all of the above would allow me to have a break from them and the brothers from each other
- These are the reasons I hope we will get respite care / short breaks for our son as part of our parent carer assessment package for To give our family a better quality of time life Ect

- I am currently pregnant with my 3rd child, my son is very demanding and challenging and Lancashire break time is a much needed respite for me at this tiring time whilst also looking after m
- Didn't know my son was allowed
- Don't get a break only when the careers come in to bath my daughter for 45 minute
- These are the reasons I would like to use if anything was available
- Children to see their friends and maintain a routine. Spend time with my other children, help me be a better carer on their return, allow me to attend college, allow me to work.
- If we could access lancashire break time the above is what i would use it for . I feel my child is missing out due to his medical condition.
- We cannot access this as Harry, is to young and the times wouldn't work with my working hours
- I cannot use the service because there is nothing that caters for a 6 year old who needs 1:1 but if there was I would use it whilst I was at work!!
- Almost all of the list apply. This service is needed so much and more of it.
- Never used
- I didn't know about this service
- I have selected three but it is absolutely for all the reasons and more He was not able to access mainstream child care provision and I couldn't have worked without this
- I haven't been able to access short breaks for some time now
- To allow me to mentally rest even if only for a couple of hours, sometimes that's what can get us through a week knowing we have that 2 hours on a certain day
- Allows Emmerson to mix with other kids as he is not safe to play out on his own.
- Go and see my own parents and other immediate and extended family on my own
- For my child to attend a provision which supports her needs, where she is safe and feels secure, we're the staff have specialist skills to meet her needs
- I don't use this
- Use them or lose them but they are not very well advertised and people don't know much about them.
- Only three things? I think we all try and fit everything into the limited time we have respite care for. I would have ticked everyone of these apart from 'undertaking education' and 'enable
- They help us so much with behaviours and getting my child out and about
- I wanted to select them all
- All of the above!
- would like to be able to go to work, unfortunately I am unable to find care for my son with his complex needs
- My child likes to feel independent of me
- All of the above but also to allow my daughter to enjoy something enjoyable during school holidays
- Meet other children with similar needs so not alone
- Not attended in last 12 months as do not meet our family / child's needs
- All of the above apply as I have other children ... unfortunately we are only allowed to tick 3 answers which is inappropriate
- To ensure we can carry in coping as a family
- Be around different people
- Social services will not help, even though they are partly to blame them for not assesing us early enough which caused attachment issues... It took nearly 11 months where my nephew was place there are more than 3 things mentioned there are 7 things on that list that are appropriate for us
- Sanity
- For my son it would be a chance to enjoy a positive experience.
- It won't allow me to select all main reasons so listed here Catch up on sleep Undertake family and household tasks (for example, attend appointments, shopping, cleaning) Spend time with my
- Spend time with husband
- Enjoy leisure time as a family



## **As a parent or carer, what is most important to you when considering a short break activity?**

*Please select one option only*

32 Choice of activities

38 Location of activity

108 When activities are available (for example, school holiday time, term time, evenings, weekends, after school)

27 Cost of activity

52 A range of activities that meet the needs of me and my family

13 How many hours the activity lasts for

33 Other

If you have selected other, please type details in the box:

- Suitability of activity for my child's needs I don't feel choice of activity covers that
- Whether it meets my child's needs and appropriate for their ability.
- All the above
- That the staff can meet the needs of my children
- The care offered to my child
- Never used one
- Not tried any
- A place where staff are experienced and understand my child. Where my child can be their self and feel happy. I have peace of mind that my child is safe!!
- Consistent knowledgeable staff
- How many hours
- I probably choose because of all the factors above in away not just one thing
- If the staff have experience and the facilities available to meet my child's need
- The experience of the staff providing services
- My sons behaviour is very challenging and finding a holiday club for when he's off school that is suitable and can meet his needs in an understanding and caring way is very important to me.
- Whether the staff are trained to look after and be responsible for my child. (He has lots of special equipment and has epilepsy rescue medication - mainstream holiday clubs won't take him)
- The quality of the activities. They need to meet the needs of my disabled daughter ensuring that she is safe and happy.
- will my son be happy there, activities geared towards his needs and preferences, and will the staff know how to meet his needs. Is it safe
- Staff are trained
- The ability of staff to meet my son's extremely complex needs.
- Whether my child feels happy and secure and able to access the activity.
- Get rid of the service, waste of public money
- Choice is based on the support offered to my child during the holiday activity
- There is not one thing that is the most important - an excellent activity might warrant travelling further in order to attend.

- Specialism of placement-training and experience
- Understanding and caring staff in a place I know my son will be safe and well cared for and staff that are trained to deal with his challenging needs
- All of the above
- That the providers can meet his needs.
- Again, all of these are relevant. His equipment is at the special school he goes to so it makes sense for him to go there to access his equipment and to be able to have his personal care do
- That I can get a break with people I trust to look after my son
- If staff supporting can meet my child needs
- My child can only go to the respite home due to his very challenging behaviours
- Knowing my child is safe
- My child socialising with friends and being able to play with people instead of being stuck in the house
- na
- All of the above but most importantly the capabilities of the organisation to meet my daughters needs this question appears flawed when considered on a practical level, it forces a single answer when in fact it's the combination of factors which makes the service usable, the wrong location
- All of above
- Knowing my boy is being looked after by people who can cope with his many challenges
- Location as well as activities that meets needs of all my children
- Knowing my child is safe and looked after while not in my care. Also knowing the activity is suitable for my child (not me)
- Both location & when available
- The safety and suitability of and for our child.
- Ensure it would be something that would be enriching for my son
- The quality and experience of the staff and the appropriateness of the activity
- I would of also chosen cost & location..those 3 factors are the most important
- Not as cut & dried as that. Activity has to be right for him but also timing, cost Location very much linked to where/distance for whether or not knock about or travel home, which in turn

### **Short break services of the future**

#### **What additional support, if any, does a short break service need to provide?**

*Please select as many as apply*

55 Specialist support or equipment for hearing or visual impairment

131 Personal care

92 Specialist support/training and/or equipment required for complex medical needs

213 High levels of supervision

62 Specialist moving and handling equipment and staff trained to use this

24 Don't know

34 Other

If you have selected other, please type details in the box:

- Social groups for high functioning children is desperately needed across Lancashire
- Staff trained in dealing with developing social skills. Trained in dealing with behaviour issues
- Specialised support and training in challenging behaviour and SEND
- None
- Dont use this service
- experience in conditions of the children & young people they support!!
- Break\_Time\_Final
- Training for challenging behaviour
- My child cannot access any LBt provision due to their complex needs
- None of those additional things are required
- Enthusiastic, good-humoured staff to help motivate my child to socialise and try new activities.
- Proper support for the needs of each individual that attends not on numbers some children need 2 to one support
- Provide a safe environment with specially trained staff. Small groups.
- Better range of transport facilities to transport wheelchair users
- Skilled staff with behaviour management skills
- Enough staff to provide a range of activities for a range of needs
- More of them, I've never been offered one
- The ability for my child to be himself without being judged and without the regular telephone calls we used to get from mainstream clubs!
- well trained staff,
- Allows him to be himself, join in a club just like all other 11 year olds want to
- A placement familiar to my child is important
- Continuity of staff who know my childs needs and understand their behaviours.
- An environment that accommodates the needs of the children, like all the things listed above. But mainly a place where my child is respected despite the differences and where he is allowed
- To be available to Sen the sane as normal children holidays clubs 9-5 after school clubs 3-6 how can we stay employed without support in the holidays i was a financial advisor and has had t
- Social boundaries
- Familiar, caring, regular staff for the children
- High ratio of adult to child ratio with specialist training
- There are parents who cant even access a holiday club at a special school because their child needs constant supervision. They have no choice whatsoever. This is heart breaking. So everythi
- Experienced and confident staff
- The ability to meet the needs of very challenging young people
- Residential- None, they are perfect
- na
- Team Teach, sign lango
- Understanding of each child's additional needs, in order to keep them safe. The ability to help that child have 'fun' and access age appropriate activities with support that otherwise they
- Appropriate peers
- Fun and engaging activities delivered by trained and experienced staff
- services should be able to meet a range of complex physical and mental needs, in the same way that educational establishments must cater for the full range of needs
- The ability to help teach social skills.
- Staff training is number one priority
- The respite home my child goes to provides everything my child needs
- It's a safe space where my can be himself and be with friends who accept him.
- Educational and fun to learn.
- Use of makaton/ sign supported language and or PECS
- These are most important to me However my children do not have hearing or sight impairments. Staff need to understand the children and be competent while looking after my children. I expect longer hours for working parents, drop off service.
- All of the above depending on individual needs. Also training/support for staff & volunteers on

supporting children complex need/presentations.

- If you have selected other, please type details in the box
- Overnight/weekend care
- More variety of activities
- Medical training.
- Communication - ability to sign/use pecs/ understand what my child is trying to say. Appropriate and quality Interaction with my child - engaging with them (inclusion.) Person centred plan
- Whilst my son has been able to benefit, despite all his needs and limited options on short breaks, I am aware that the parents who need the support the most currently have no options, no
- Mental health and wellbeing support

### **Which of the following, if any, would you like a short break service to offer?**

*Please select as many as apply*

- 170 More choice and innovative short breaks (for example, local leisure activities such as the zoo, theme parks, adaptive caravan family holidays, beach huts)
- 131 After school clubs
- 224 Holiday clubs
- 138 Full-day short breaks
- 158 Weekend short breaks
- 151 Breaks that are near to where I live or I can get to easily
- 82 My child/children can attend with friends
- 92 My child/children can attend a short break activity with children with or without special educational needs and/or disabilities (for example, a local sports club, scouts, guides, youth club)
- 160 Plenty of availability
- 35 Short breaks in the home
- 113 Overnight short breaks
- 74 Online booking
- 164 Short breaks my child/children can go on without me (for example, day trips, leisure activities, short holidays)
- 102 Short breaks we can attend as a family (for example, daytrips, leisure activities, short holidays)
- 6 Other

If you have selected other, please type details in the box:

- Need to be age and ability appropriate. They are very much geared towards low level activities like slime making, which is unsuitable for a teen who is high functioning and would like to do
- Short breaks that can take older teenagers and young adults together, to support transition
- Dont do this service
- We don't fit criteria for direct payments when over night respite went that's what we missed the most we have no family support no one takes my child for sleepover a child that wakes I woul
- Advance booking for planning work (not one weeks notice of availability as currently get)
- I know that social workers tell families that overnight respite doesn't exist because lots of the houses were closed down
- I have been unable to find any after school club or holiday club that is able to meet the needs of my son.
- I would like to select all, but that does not help the council focus resources. we need service sto do more than just care for our childs physical needs , services should offer meaningful,
- Lancashire council should look towards Blackpool re aiming higher organising events and having a service that can sign post families and offer families a chance to go out together and soci
- Suggestions in option (1) are fine for those with fewer needs but not for more complex who are also the ones most demanding on families I've a child who doesn't sleep much for medical reaso
- Basically need activities where he is safe and accepted with people who can meet his needs so he can socialise and develop his social skills which is unable to do in other environments

**We are thinking about what we could do differently to improve our short break services. How strongly do you agree or disagree with each of the following?**

*Please select one option for each statement*

	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
There should be more holiday clubs	238	43	17	2	2	5
There should be more evening clubs	145	65	61	8	4	13
There should be more weekend clubs	186	65	32	7	2	8
There should be more short break activities and clubs provided by schools	154	62	48	10	9	8
There should be clearer eligibility criteria for accessing short breaks including overnight short breaks	150	79	49	5	3	10
There should be more information about short breaks	191	76	22	3	1	4
Short break services should only be accessible after a needs assessment	63	46	71	51	45	9
Access to short break services should be fair	198	59	26	3	3	4
Families should be able to access different types of short break activities to meet their needs	220	58	16	3	1	4
There should be more involvement of parent/carers and young people in making sure short break services meet needs	158	88	34	3	3	4
The parent/carer financial contribution to short break activities like Lancashire Break Time should be increased	56	36	98	44	43	13
There should be an increase in the different type of short break activities to choose from	147	84	47	6	3	4
Children and families who receive short breaks after an assessment should also be able to access other types of short break activities (for example, group activities like Lancashire Break Time)	159	66	47	4	5	9

**Q9 Do you have any any other ideas on how we should do things differently to improve the short break service?** *Please type your ideas in the box*

- School holidays are a massive issue We don't mind paying for holiday cover but there I no services available! More families would use it and contribute if you had more provision for Sen kids Please provide more provision for Sen kid
- If been told my daughter can no longer attend any short breaks sessions as she has a package of care provided by social services. Yet again I feel that the most severely disabled are being discriminated against as she can no longer attend any of the services she enjoyed. I do feel a lot of children now on these lancashire break time short breaks can attend a 'typical' non specialised holiday or after school club session and the criteria does need looking at again!
- Remove the restrictions on attending Holiday clubs that has been introduced by certain providers. This is unfair and discriminatory and not allowing those parents with children with additional needs to have equal access as those children without additional needs.
- The current service works fine for us.
- Cater for younger children my sons 3 almost 4 and can't attend any because of his age and it's not fair he needs to be included
- Help children who have a medical condition that needs a trained staff member at all times. Help schools to keep cost low when offering after school clubs / holiday.
- We need after school care and half term clubs for children aged 5 and above as we have none!!
- The creation of new short break overnight units should be continued as agreed in a previous consultation. Overnight breaks outside the home should be offered predominantly to children who have the most complex needs. Although an holistic family approach is required, a clearer eligibility criteria is imperative for short overnight break access to ensure children with the most complex needs can be served accordingly. In addition annual reviews of children accessing the overnight break service should be completed as some may have progressed to a point where their social life can afford them overnight stays with friends and the use of 'mainstream' activities such as the cinema, swimming, family holidays abroad etc.
- Parents should be made aware of these services. There needs to be more available then more families can benefit from them. Regular respite and breaks is imperative in caring for your disabled child.
- Provide schools with information letters to be sent home from school. My son is 9, he has downs syndrome and I still don't know what services are available for him?
- more choice made easier to access, no social worker required to get funded places.
- More availability of short breaks for children who need a high level of supervision without parents being told to apply for direct payments.
- Abolish it
- More advertising let people know, I don't know about them I really would like to see mire short break holiday s
- Ensure their is appropriate staffing in place so that children who require additional support are included more.
- Should not be based on an assessment, if a child has been through a formal assessment and has been assessed as having additional needs i.e education, health and care plan then they should be able to access short breaks. If it relies on assessment and you child doesn't meet the criteria where does that leave the child/ family. There should also be more provision for holiday clubs for special needs children. My child can only attend a holiday club for 2 days per week due to the numbers of children accessing the provision, mainstream children can have 5 days per week, this needs to change by having more holiday clubs which cater for special needs children so the demand is spread out.
- Inform people
- Once a month for a Sunday at Barnardos respite is not enough when I have no other respite available. If more clubs/venues were available then places wouldn't fill so fast. It needs to be a fairer system.

- Having 3 young people all with SEN I would think families would benefit from short breaks or a holiday where the children/young people could stay in their own home and have care provided in their own familiar environment while their permanent carers could take a break possibly away. I think the carers needs should be taken into consideration too. I find that there's not enough flexibility in how a family's wishes are accounted for.
- There should be more inclusion for east Lancashire. Most of the short breaks are central and west Lancashire. Parents struggle to get to short breaks from east Lancashire.
- You said previously that they were only available to children without assessed need - then said they could attend with an adult - effectively meaning that my child can rarely go, as the hours available to me through direct payments are almost all used in the school holidays on the one day I work. If there is no appropriate activity that day, then she cannot go. There is very little else for her to do in the community. In addition, my local holiday/Saturday club only caters for up to 16 years old, so my daughter is now barred from this, which she loved - and she still has another 2 years at school.
- the service is oversubscribed and thus should be more availability, granted some may cost more than others but it is a service needed and a service I am prepared to pay for.
- Lack of local holiday clubs during school holidays is an issue for working parents of disabled children. Many cannot access the generic holiday clubs that many (including my 2 youngest) go to. They need to be able to socialise with peers but with support and supervision from qualified staff in an environment that suits their needs and in which they are safe.
- Create a bank of pre selected suitably trained staff with DBS who can be used for direct payments and short breaks at short notice.
- Wider local provision- Bacup area is massively under sourced More availability especially through the summer holidays
- Basically do the best you can for our children and family listen to us
- Our experience is that there are too many organisations offering groups and because attendees is shared between them all the groups cease after a short period due to poor uptake. You should have less choice and activities provided by only a few organisations who are properly trained to understand the behaviours and meet the needs of children/young people with additional needs. This would improve continuity of staff and locations for our children and also improve quality and safety of service provision.
- Include parent views and needs, after all we live it daily and therefore we are experts in our children. Be transparent and not make us feel like we have to fight for everything. Most of all, remember not all children with additional needs will receive a statutory assessment, please don't exclude them, those families need a break too
- I don't think we Look at the bigger picture, for example if I had more facilities provided via Lancashire break time for my daughter I could still hold down a proper job and therefore you'd save costs in benefit pay outs, this is the same for quite a lot of Sen parents not just us.
- If it wasn't for Barnardos Emmerson would not mix with other children outside of school and would be cut off from social events
- I am aware that funding can be allocated at short notice. However, having varied breaks particularly for children who have significant physical needs to partake in activities out of an indoor environment would be good. A child sitting in a room all day and a unable to take part in activities can be very frustrating. As parents/carers we want our child to be able to experience different things
- You need to ensure short breaks remain in place to ensure you provide safe opportunities that meet individual need. Without this you increase risk of isolation and poor mental health for carers
- Cutbacks have reduced the availability to parents and reduced the no. Of weeks with services offered in larger holidays.
- I'm not convinced that it needs to be done differently, but then, I only access the holiday clubs and wasn't really aware of all that was available.
- I have never been given the option for this.
- Offering more days of holiday club in the 6 week holidays for parents that work and need a special

needs holiday club for these children

- We like how it functions now, it meets our families needs, the increase in holiday club to £ 20 a day has been difficult and caused us hardship. The previous £10 a day was fairer. In the questionnaire you ask should access be fair? It is difficult to define fair when assessing children with additional needs and their families as the families are all so different and how we manage/cope is very different. Plus how we manage/cope fluctuates, we should be able to access the clubs/support in a fluid way, attend more when we need more.
- There should be more respite available for more children to access and it should be free to the family. After all it's cheaper than said child being placed into care full time!
- More availability of engaging activities and trips fully supported No
- Better information. More for physical disabilities with suitable premises for wheelchair bound children.
- Do not add a layer of admin for parents. We have enough form filling and phone calls already. I don't want to spend my precious day in the school holidays filling out forms for my next one. Perhaps with more consistent support parents like me could apply for non term time roles and jobs we are trained to do and want to do and therefore earn more money and pay more taxes. With regards to it being means tested. I don't think your income has anything to do with how well you can physically emotionally and mentally come to terms and 'deal with' caring for a disabled child. We did not volunteer for this role and I'm sure many of us, given the choice, would want rid of their child's disability. Having a disabled child means the whole family is disabled. It limits everyone involved in all areas of life 24/7/365 days of the year. Life is hard enough. And when you leave hospital with a tiny human, grieving and facing the unknown, you expect that services will be there to help. If society and public
- Other short breaks and long breaks, I need to re-charge my batteries
- Give parents more information about what is available and what the options are.
- I only found out about overnight short breaks by accident I have really struggled with my child at home and having direct payment workers helps a little but sometimes it's hard because it's hard to get the same staff and a consistent approach that my child needs. Since he started overnight breaks I have needed less other services as it's all offered under one roof I believe that having a complete rest away from my son really helps me and the family care for him and keep him at home with me and not have to consider a residential placement I can spend time with my other daughter as she was beginning to have problems because my son caused so much chaos at home. Overnight shift breaks have been a god send
- The Overnight respite home my child goes to has required investment for years. We were consulted on this and it was agreed many years ago. The staff are excellent and go above and beyond for my family. My child would be in care if I couldn't get these breaks.
- The clubs are great for kids who can cope with them. All the kids with challenging behaviours end up not being able to go because staff don't have the skills to look after them. My child goes to Evergreen and my friend goes to Alexander House. They have staff that know how to support our children and give us a break while we know they are safe happy and having fun
- Have clubs that are able to meet the needs of children with complex needs. Staff better trained at Barnados for children with special needs.
- Holidays are horrendous for our son! He liked holiday clubs but when we try and do the usual things with his sister without disabilities he can't cope and this impacts on us! We need provision so we can take holidays all together
- Sailability at Burwain Sailing Club
- Lower the cost of trips so that more children can access them. My child cannot go on any trips because they are completely unaffordable for me
- More on offer during school holidays! Up until a couple of years ago there were a few places providing holiday clubs near Chorley eg Rainbow House and Chorley Reach up and Go. Now there seems to be only Barnados which my son enjoys but each child only gets 1 day per week which means the rest of his care throughout the summer is provided by me. This is exhausting and affects my mental health and also restricts my other children.
- For children who have very complex needs and challenging behaviour there is a lack of providers and



availability. Children who are mild / moderate can be looked after by Barnardos and other LBT providers but those who are challenging miss out. It's not fair that some special schools have after school clubs but not all it is a post code lottery. There is not enough choice in providers and it's one size it's all not what best suits child. Not able to get PAs if you have direct payments. Families should be able to pay to top up care / activity packages if they want better service or something more individual. Big large group activities don't suit all children. Parents should pay cost of trips/clubs/ activities and the LA just pay the additional care component. I expect to pay for scouts , swimming for my non disabled child and this should be the same it's the care part that is more expensive and is above and beyond what we can pay. It's not fair that some children access clubs

- More equally distributed, in my area there is only one youth club for additional needs that meets my sons needs, but it struggles to get volunteers and support. I also had to wait over a year to get a place. If I lived in Preston, for example, I would have lots more activities to chose from.
- Currently children are not currently getting their needs met compared to ten years ago, the demand is huge now, and the resources are much less. It's not easy to solve this problem but families are being robbed off and expected to do the impossible on a daily basis and that is wrong. Where children have severe / complex needs support needs to be provided earlier (when a small amount can go a long way) - waiting for families to reach crisis before they see any help is not cost effective or humane. Once families do reach crisis currently they are then treated with disdain. Even though resources are few, there is never a need for social workers and other "professionals " to treat parents as though they have somehow failed or are asking for the moon. Many have already exhausted all their resources and are carrying on despite the odds, they deserve to be treated with respect.
- Currently those with the greatest need are discriminated against. If their child has very challenging behaviour th
- Holiday club to continue to age 19 no
- Known staff/ continuity is essential.
- There should be more service providers. Budgets should be increased to entice other providers to tender.
- more services are not necessarily the solution, dilution of funds causes many issues and economies of scale and accessibility must be carefully balanced. fewer providers with a greater range of availability and options should be explored. new contracting models should be explored based on cost and volume so that LCC is not funding empty spaces. LCC should review services offered by other authorities and explore options to jointly commission services with health, education, sports England, national trust, etc. again there are so many funding bodies who contribute to the same outcomes, but the funds are diluted too thinly among too many providers to make big impacts in any local area. joint commissioning takes time but would eventually save the tax payer money. it would be great to have a trusted flagship service in each district pooling the funds from different sources. the authority should consider authority owned or controlled businesses to avoid diverting public funds toward p
- Information on how to access services upon diagnosis
- Advertise them more? My son is 10, had his diagnosis since the age of 5 and this is the first we've heard of such a service.
- Consider working parents, short breaks should work with school transport arrangements, we can't work and be available at any time. Help parents work by using short breaks to offer wrap around care. Consider the whole family not just individuals. We want to help ourselves but the offer is too restrictive. Asses us on our needs as a family to ensure we are able to keep employed and meeting all our children's needs.
- Make it available for all and allow opportunities for those who have never accessed this service , due to the resin it is always booked when calling to book
- My child attends these services to gain social skills. The time frame is limited with the clubs only running for a certain amount of time this meaning she doesnt get to spend quality time with the friends she makes within these clubs
- No
- Needs to be more to offer in lancaster for people that don't drive

- The respite homes in Lancashire should never have closed. Families would have used them but social workers told families they didn't exist
- I didn't know it was a thing, so I guess you need to improve your marketing. How do people usually find out about your offer?
- There are not any clubs for teenage boys. I am so desperate to find a multi sports club/football club for children with additional needs apart from the climbing at Salt Ayre in Morecambe there is not anything else available. Teenagers like gaming and technology it would be great if there was a club that was for computers. I have found some clubs on your website do not actually run any longer.
- With regard to the sports clubs it would also promote exercise and well being to young people. Please Please could we have a sports club/ football. Many Thanks
- Improve communication and advertising of breaks. Make clubs more exciting, interesting and age appropriate. Do the activities that are stated on advertising. Provide a wide variety of activity and cater for a wide level of ability. Have enough staff to be able to provide a variety of activity for a mixture of needs within groups. Provide different activities for more able children.
- Offer activities to children age 6 and under because they don't do that which I think is unfair and unreasonable to my point of view
- Direct payment should include access to short breaks as this is more expensive than normal PA hourly charges. There is no attention given to siblings of the special needs child, they usually are not given the attention and support that they need, services should be focused also on ensuring these children's social emotional development are not indirectly affected by the child's disability and goes unnoticed. Parents should also be informed on how to deal with siblings of children with disabilities. Husbands are important and forgotten! they are the ones where all the pressure is released on...
- My son as never received this service. He has only ever attended Lancashire break time groups, mainly in his school.
- No its fine
- More availability
- Level of need should be assessed not just on the child but on the needs of the whole family. This one child can cause critical problems for siblings and the mental health and wellbeing of parents.
- More interaction with existing groups in the community, Cubs, guides ect. Allowing children from an area to be part of their community.
- Should work alongside schools to enable our teachers and T, A, s who care for our children and who our children trust as they are with them everyday in a safe school environment to be able to do more activities in the community through school supervision as they know all of our children's needs already, fun adventures with staff already in place with who our children already trust so anxiety and meltdowns are eased through worry of strangers,
- Liaise with councils & leisure trusts to find availability of "SEND slots" that could be easily allocated/timetabled as designated SEND use for parents/families - to book online Ask local authority "disability champion" counsellors to visit & further help the clubs on the ground with their available grants and advise/help with any red tape that clubs have with local authorities - ask those counsellors to attend LAP meetings to improve communication between all parties and advise re funding of short breaks Encourage more facilities to offer SEND inclusive sessions where all the family can attend - SEND parents have lots of mainstream children too and finding different provision for both is impossible Encourage more SEND staff to participate in after school, weekend, holiday & short break provision - extra specialist help to families and extra income for them Encourage more leisure trust management to think about using their staff to work in allocated SEND sessions - readily available
- The council have ignored our views for years. Every time they have made cuts our vulnerable children have been hit. The council don't respect or listen to our views. We have a team within the council who don't seem to care about our children. Our families are often poor due to at least 1 adult being unable to work to meet our children's needs. Carers save the local authority millions of pounds each year yet you constantly try to punish our children and families. Lancashire county councils send department have told me on many occasions that they have no legal obligation to help unassessed young people. However they make it near impossible for children to get an assessment from a social worker. If all the

unassessed children applied for direct payments ect it would cost the council more money and also being the failing social care department to its knees. Also there is no provision for under 8s in wyre.

- There is also no respite care for our young people. Other councils are miles ahead of la you doing a fine job, keep it up and thanks.
- There isn't enough support/respite for families who have a child with additional needs. A child should be able to access supported provisions to meet with their friends. It seems this cohort of children are disadvantaged. I know my child's support provision had significantly decreased over the years. This issue is not going away and should be looked at before crisis point hits, & that parents are not burnt out.
- Keep supporting Piccadilly support services they do a fantastic job for young people with special needs
- More variety, after school and weekend clubs provision would be fab! More funding to keep services going, providing children with additional needs access to clubs within the community that just wouldn't be possible without it - it's been a lifeline to my child and family.
- Yes... We have 2 nephews and because they have a hidden disability they dont meet the criteria for respite. We need to fix our broken family and spend time with our own children who have been suffering for years
- There needs to be more local services for health and fitness i.e holiday clubs and after school clubs to improve health i.e swimming etc. The current provision is unrealistic for helping working parents the majority of parents are restricted to how much annual leave can be taken over school holidays this returns in additional stress and also no family time as leave is spent just trying to plug the gaps as no available provision. Our children need a familiar environment and as many parents i would not feel secure sending my son to a random unfamiliar provision. Need more for teenagers too.
- Would like the holiday club to continue as I have to go to work and we have no family members available to help .
- Stop refusing care. Stop telling parents that they aren't eligible for this care and hiding criteria. Stop making this so damn hard.
- Be more inclusive although children have different needs they all need support.
- Ensure the short break provision is put where the need is and not where the providers are based. Local offer information and user friendliness of the website must be improved - not just politically correct statements but actual provision. Have a long term strategy to avoid last minute funding for holiday periods - keeps young people in routine and ensures funding for providers so they can establish good quality regular activities. Allow all CWD to attend LBT activities - don't exclude those with a care package as these types of activities are the most appropriate for them. Excluding children with a care package leaves them isolated with no appropriate clubs and activities to enjoy.
- Stop causing parents stress by stopping/starting and changing services continually. Our children
- don't like change!!!!!!!!!!!!.....
- I would like to see more variety, we have a very limited choice especially in Rossendale, it's rare we can book on due to high demand and very limited places. Reducing these services anymore would have a huge detrimental effect on all parent/carers/families & the children especially.
- Listen to more than the PCF! Qu about whether all should be assessed made me stop and think because default is no but current provision is taken up by unassessed with few needs and nothing for those with greater needs. LBT providers are saying children needing 1:1 support can't attend but many also don't qualify for DPs. Caring for them is harder on families than children needing less support. Similarly those with complex medical needs have nothing when they should be top of the pile Some families need childcare in order to work - yes that is a real need but is it a respite need or requirement for suitable service they fully pay for as would for younger non-disabled child. Should working parents, financially better off than those who can't work, take up so much supply that others get nothing? A disabled child can make life tiring, difficult, etc but nothing has as much of an impact as a child who doesn't sleep as that affects all functioning of parent as well as long term detriment to
- This survey does not address the needs of young people with PMLD Please make the process easier. Please make more places available.
- Perhaps the groups that provide such facilities should work together so they don't do things on the same days so it gives more choice and availability.

## About you

### Q10 **Are you...?**

*Please select one option only*

- 29 Male
- 282 Female
- 7 Prefer not to say

### Q11 **What was your age on your last birthday?**

*Please select one option only*

- 2 Under 16
- 2 16-19
- 33 20-34
- 193 35-49
- 77 50-64
- 3 65-74
- 0 75+
- 9 Prefer not to say

### Q12 **Are you a deaf person or do you have a disability?**

The Equality Act 2010 defines a disabled person as someone who has a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities.

*Please select as many as apply*

- 7 Yes, learning disability
- 17 Yes, physical disability
- 1 Yes, sensory disability
- 18 Yes, mental health disability
- 16 Yes, other disability
- 252 No
- 19 Prefer not to say

### Q13 **Which best describes your ethnic background?**

*Please select one option only*

- 286 White
- 12 Asian or Asian British
- 1 Black or black British
- 2 Mixed
- 0 Other
- 14 Prefer not to say

How many children/young people in total aged under 18 are there in your household?

*Please type the number of children in each age group*

under 5 years old	60
5-11 years old	191
12-16 years old	153
17-18 years old	69

**Q14 Which Lancashire district do you live in?**

*Please select one option only*

43 Lancaster
29 Fylde
23 Wyre
26 Chorley
33 South Ribble
37 Preston
16 Burnley
34 Rossendale
18 Hyndburn
9 Ribble Valley
30 West Lancashire
15 Pendle
4 None of these

**Q15 Would you like to take part in future research to help us develop and deliver an improved short break service?**

*Please select one option only*

173 Yes
133 No

**If you have selected yes, please provide your details so that we may contact you for this purpose**

*Please type details in the box*

Name	172
Telephone	139
Email	171

**If you have any queries about the questionnaire please call 01772 532509 or email  
Find@lancashire.gov.uk**

**Thank you for completing the questionnaire.**