



Short Breaks Survey

September 2023



What parent carers told us about their experience of short break services and childcare

Introduction

South Glos Parent Carers (SGPC) CIC asked the members of their forum to complete a survey detailing their family's experience of short breaks services and childcare.

When considering the reach of our survey, we discovered a barrier with the term 'short breaks'. Many parent carers either didn't know about the short breaks provisions available or didn't realise that they were applicable to them. In order to make our survey more accessible, we felt it necessary to use a variety of titles in the questions to highlight the various short break services available, including 'childcare', 'holiday provisions', 'activities', 'groups', 'respite', 'breakfast/after school provision' and 'days out'. For the purpose of this report, we refer to these as short break services. More information about the short break services can be found on the Local Offer [here](#).

The survey was in three sections to help us understand what families need:

- The impact of suitable childcare
- Access to activities, groups, clubs, days out or sessions organised specifically for children with an additional need (referred to as SEND sessions in this report)
- Access to activities, groups, clubs, days out or sessions available within the community to any child irrespective of whether they have an additional need (referred to as community sessions)

The survey ran from the 31 August - 5 October 2023 and was completed by 237 parent carers. This report details the qualitative and quantitative feedback received. Any information that may identify a child, parent carer, professional or educational setting has been removed from comments to retain confidentiality. The information gathered in this survey was to enable SGPC to represent the lived experiences of their community at meetings they attend.

SGPC is the local parent carer forum in South Gloucestershire as recognised by the Department for Education. Our community are parent carers of children aged 0-25 who have a Special Educational Need and/or Disability (SEND). We work co-productively with service providers and stakeholders, to help shape services. Details of our full range of services can be found on our [website](#).

We are grateful to all the parent carers who responded to this survey, we appreciate you taking the time to tell us about your lived experiences and allowing us to share them.

Thank you.



Executive Summary

Overview:

For most questions parent carers were asked to tick all responses that applied and therefore the total % may add up to more than 100, however this provides a clearer picture of the impact of short breaks for individual families. For example, 199 respondents answered the question regarding outcomes if children are unable to access short breaks. 66% responded that it affected their mental health. However as 1,114 ticks were received across the 15 possible outcomes, that response accounted for 12% of the overall responses. While this still demonstrates the highest impact for families it does not demonstrate how much families are impacted.

81% of families have two or more children with 59% of families having one child with an additional need and the remainder having two or more children with an additional need.

86% of children within families were of primary school age, 61% of secondary school age and the remainder being of early years or post-16 age.

17% of children have a social worker and 3% were not sure if their child had one.

Some of the responses relate to all children as childcare and access to groups and activities is important for all the children within the family, irrespective of whether they have an additional need. Some families would like childcare or access to groups for their child with an additional need and others would like activities that the whole family can access together.

86% attend a mainstream setting, 7% a resource base attached to a mainstream school and 24% a specialist setting. The remaining 9% attended other settings which included Pathways Learning Centre, PLC Cotswold unit/hospital education, independent setting, Elective Home Educated (EHE), Education Otherwise than at school (EOTAS), mentoring or were Not in Education, Training or Employment (NEET).

Parents reported a broad range of needs/disabilities, identifying the top three needs as Autism, Attention Deficit Hyperactivity Disorder/Attention Deficit Disorder and sensory processing difficulties – together accounting for 36% of the responses.

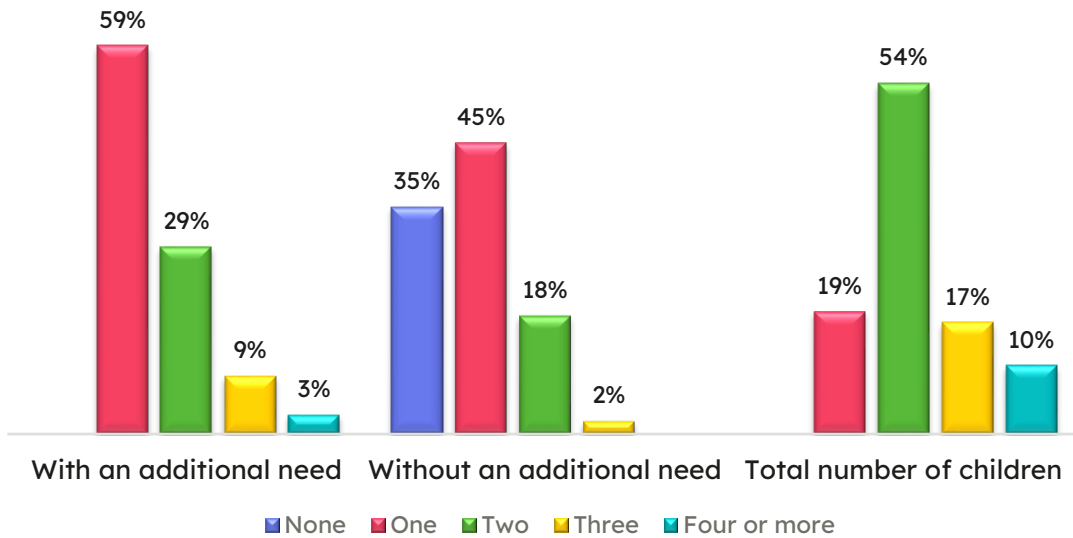
Key Findings:

- 27% of families have **accessed organisations commissioned by South Glos Council** to provide short breaks. The three most accessed were Brandon Trust holiday playscheme, Special Friends Club and Breakthrough Mentoring.
- The three main **benefits to families for their child to access childcare, SEND sessions and community sessions are:**
 1. To take part in activities/experiences
 2. To provide them with new experiences
 3. To meet and socialise with other children and young people
- The three main **outcomes for families if their child was unable to access childcare, SEND sessions or community sessions were:**
 1. Respondents felt stressed, overwhelmed or anxious and their mental health is affected
 2. It negatively impacted the child's wellbeing/mental health
 3. Respondents felt exhausted and their physical health was affected
- 41% of families **have accessed, or wanted to access, childcare** for their child to enable them to work or attend education or training etc. Childcare may include holiday clubs, childminders, breakfast clubs, after school clubs etc.

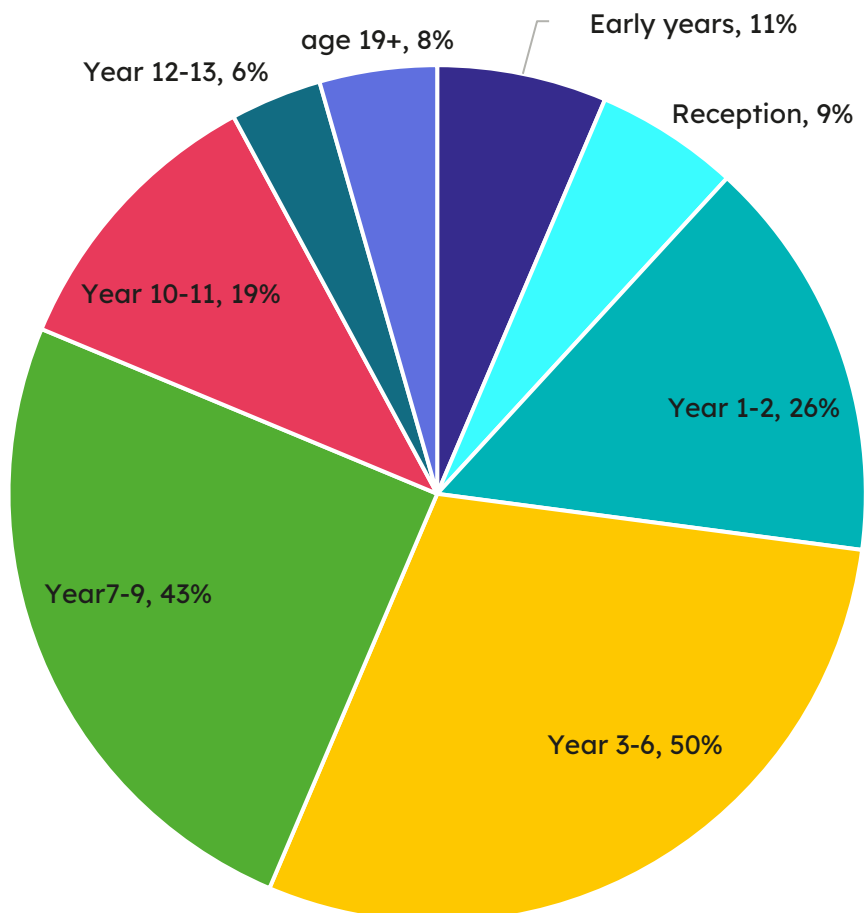
- 54% of **respondents work** part time, 28% full time and 9% unable to work due to caring responsibilities.
- 3% of families **can access childcare** at weekends, 35% in school holidays, 8% in evenings, 31% after school and 24% before school.
- For those parents **able to access childcare**, 36% found childcare for the days or hours they needed, 43% for times that partly met what they needed and for the remaining 21% it was not for the days they needed but was all that was available.
- The three **main reasons for families being unable to access childcare were**:
 1. Provider could not meet their child's needs
 2. Respondent unable to find information on suitable childcare
 3. Suitable clubs were oversubscribed
- Where families were **unable to access childcare when needed**, the main three things they did was: to use help from family or friends (42%), use holiday leave entitlement (36%) or reduce their hours and lose pay (28%). 15% of respondents do not work due to problems finding childcare and 11% work term time only for the same reason.
- 52% of families **accessed SEND sessions** during the last year. Children may have attended with or without siblings and parent carers.
- 9% of **children have accessed** mentoring, 5% overnight/residential break, 24% SEN/quiet session at a mainstream event, 8% a weekend break, 28% a day trip, 26% a club and 40% activities that are organised for children with additional needs. Many more families wanted to access these SEND sessions but were unable to for a variety of reasons.
- Families **attended SEND sessions on** evenings (16%), weekends (15%) and during school holidays (27%). This compares to 64% of families that wanted to attend these activities during evenings, 69% wanted to attend on weekends and 89% wanted to attend during the school holidays.
- The three **main types of SEND sessions that families were able to access were**: a day out with family (67%), activities with family (61%), clubs and groups with family (41%). Less than a third of children were able to access SEND sessions by themselves.
- The three main **reasons for children being unable to access SEND sessions were**:
 1. The provider was unable to meet the needs of the child (39%)
 2. Suitable clubs being oversubscribed (33%)
 3. Respondents being unable to find information on suitable clubs (31%)
- 51% of children with an additional need **accessed or wanted to access community sessions** during the last year.
- The three main types of **community sessions that children were able to access were**: days out (47%), activities (40%), clubs and groups (36%).
- Families **attended community sessions** on evenings (26%), weekends (23%) and during school holidays (32%). This compares to 63% of families that wanted to attend these activities during evenings, 63% wanted to attend on weekends and 85% wanted to attend during the school holidays.
- The three main types of **community sessions that families were able to access were**: a day out with family (70%), activities with family (61%), holidays/break with family (43%).
- The three main reasons for families being **unable to access community sessions** were:
 1. The provider was unable to meet the needs of the child (43%)
 2. Too expensive (38%)
 3. Respondents being unable to find information on suitable groups (31%)

About the respondents

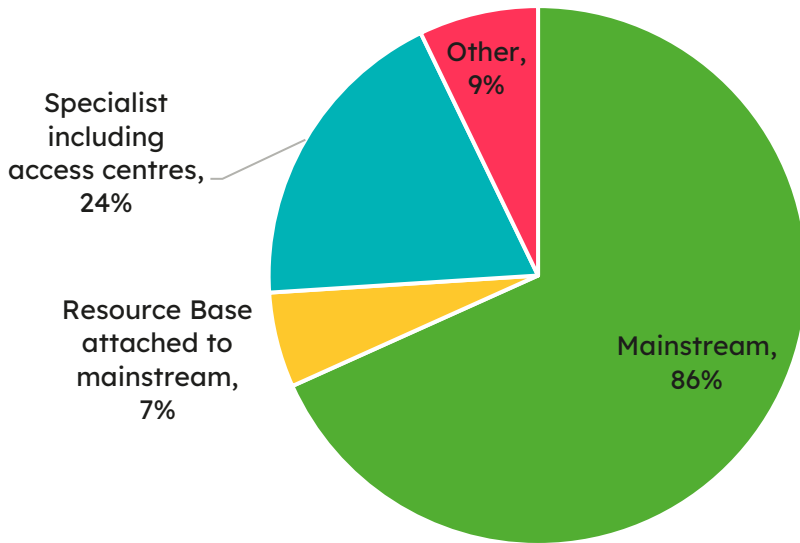
How many children are in your family?



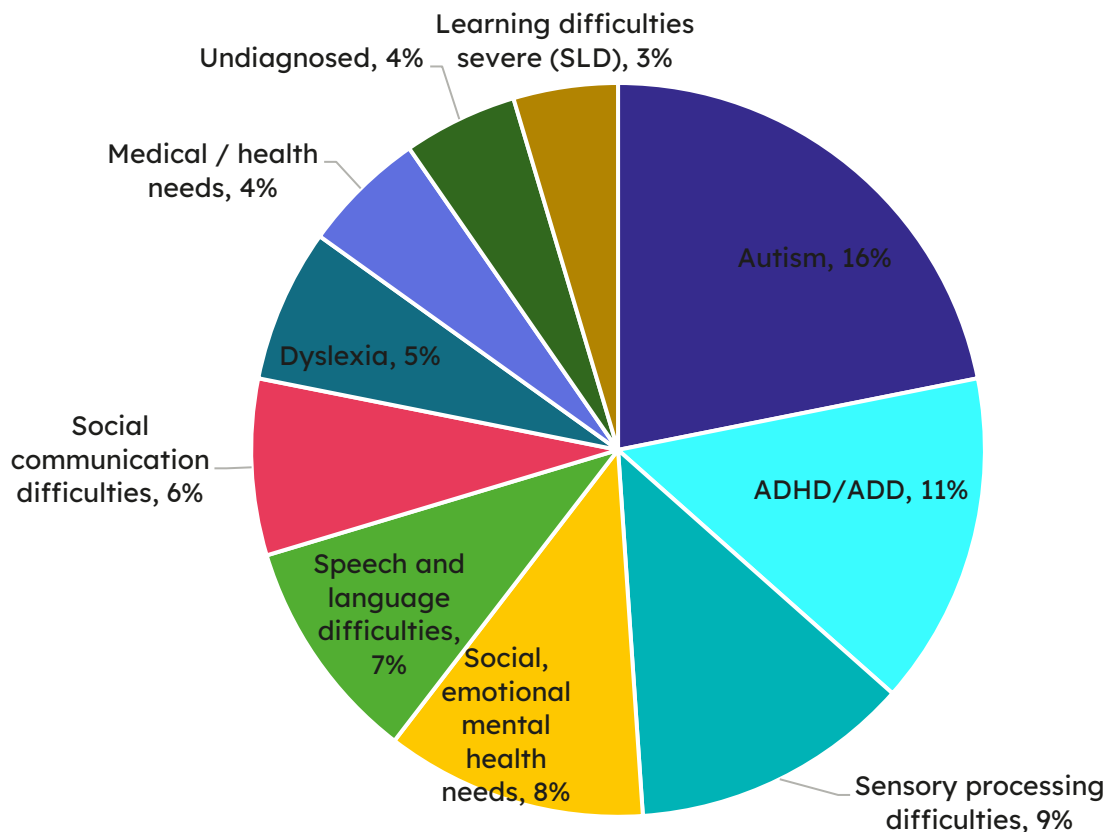
What years were your children in at their settings?



What type of setting do your children attend?



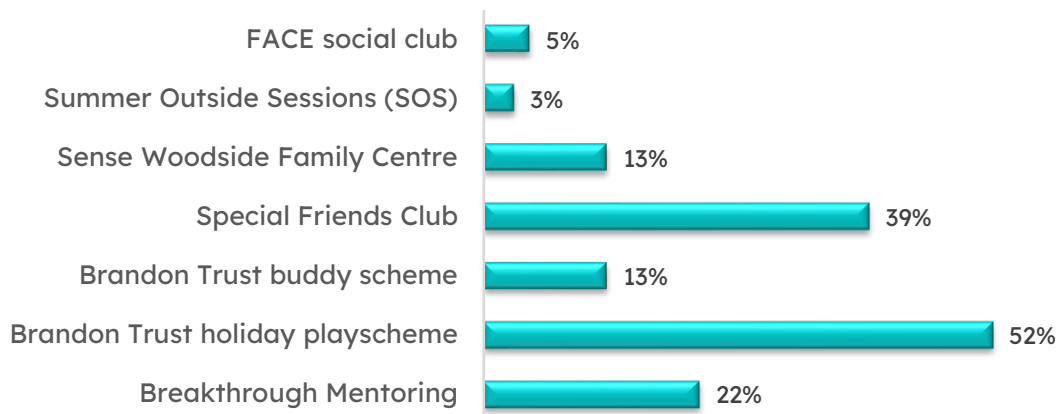
What are your children's additional needs/disabilities?



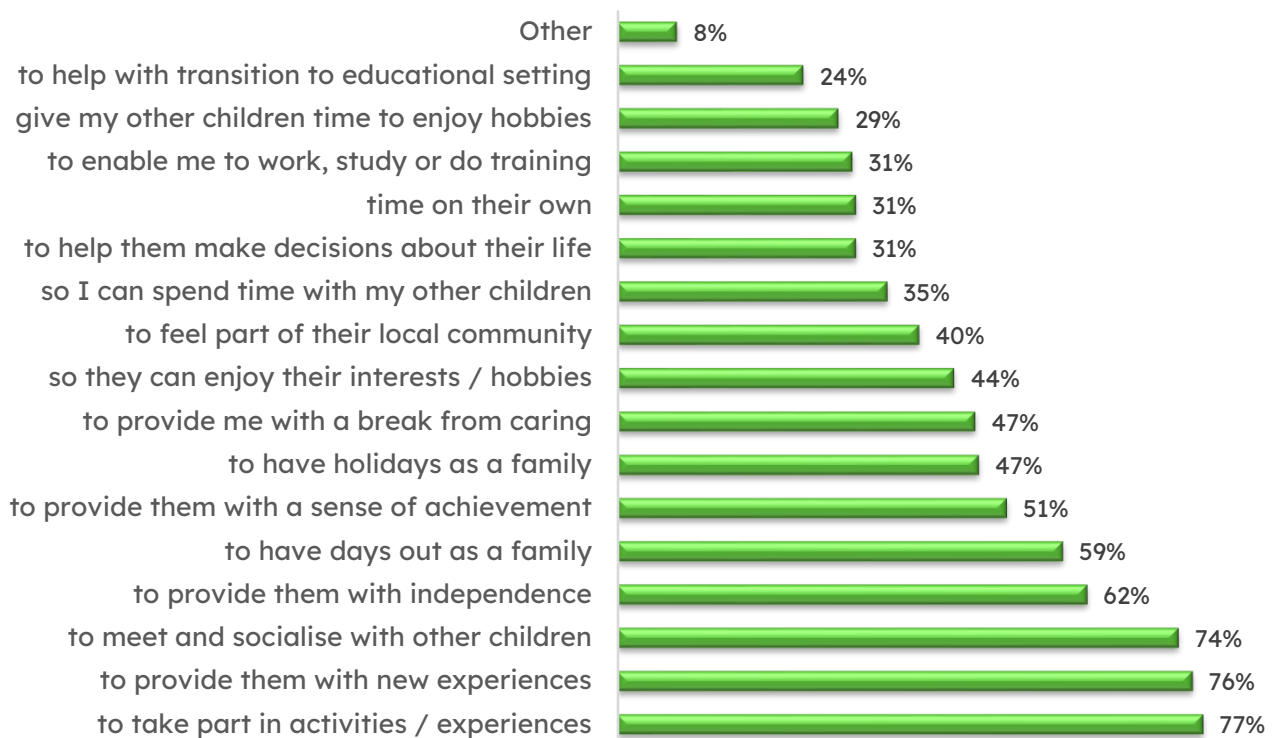
Other includes:

Global Development Delay, physical disability, neurological disorder (e.g. Cerebral Palsy, Epilepsy, Hydrocephalus, brain injury), hearing impairment, visual impairment, genetic/chromosome disorder, Multi-sensory impairment, Chronic Fatigue Syndrome/ME, Down Syndrome, profound multiple learning difficulty (PMLD), Syndrome Without A Name (SWAN), cancer, scoliosis, Obsessive Compulsive Disorder, Cerebral Visual Impairment, non-verbal, dysgraphia, dyscalculia, Hirschsprung's Disease, Crohn's disease, polymicrogyria, GNB1 Syndrome.

Has your family or child accessed any of the following commissioned services?



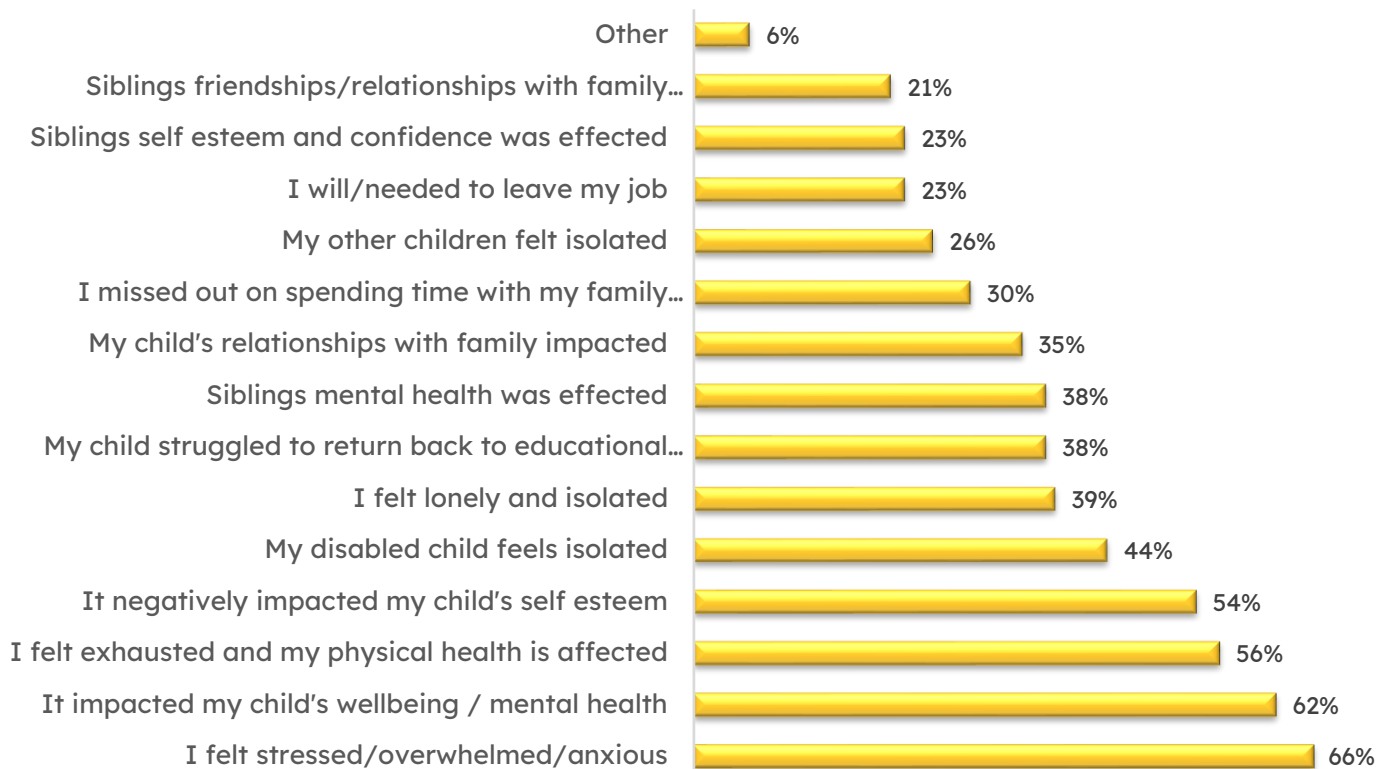
What are the benefits to your family for your child to access short breaks?



In the 'Other' category, parent carers said:

- Learning life skills away from home and school environments.
- To provide respite from their daily grind and allow them to be free and in fresh air, natural daylight and within nature
- Make memories
- To keep younger sibling safe
- So they can participate in activities every other child can as they want to feel "normal"
- to recover energy/strength/wellbeing after all struggles
- To be heard and seen
- To prevent boredom and to break the cycle of constant screen time as cannot access most activities

What were the outcomes if your child was unable to access any short breaks?

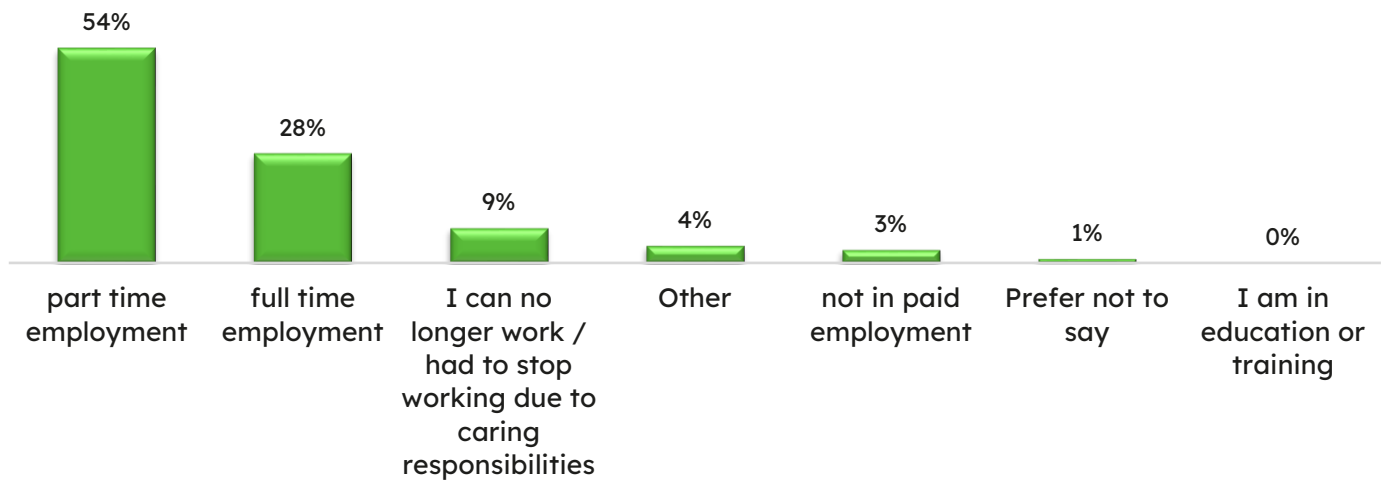


In the 'Other' category, parent carers said:

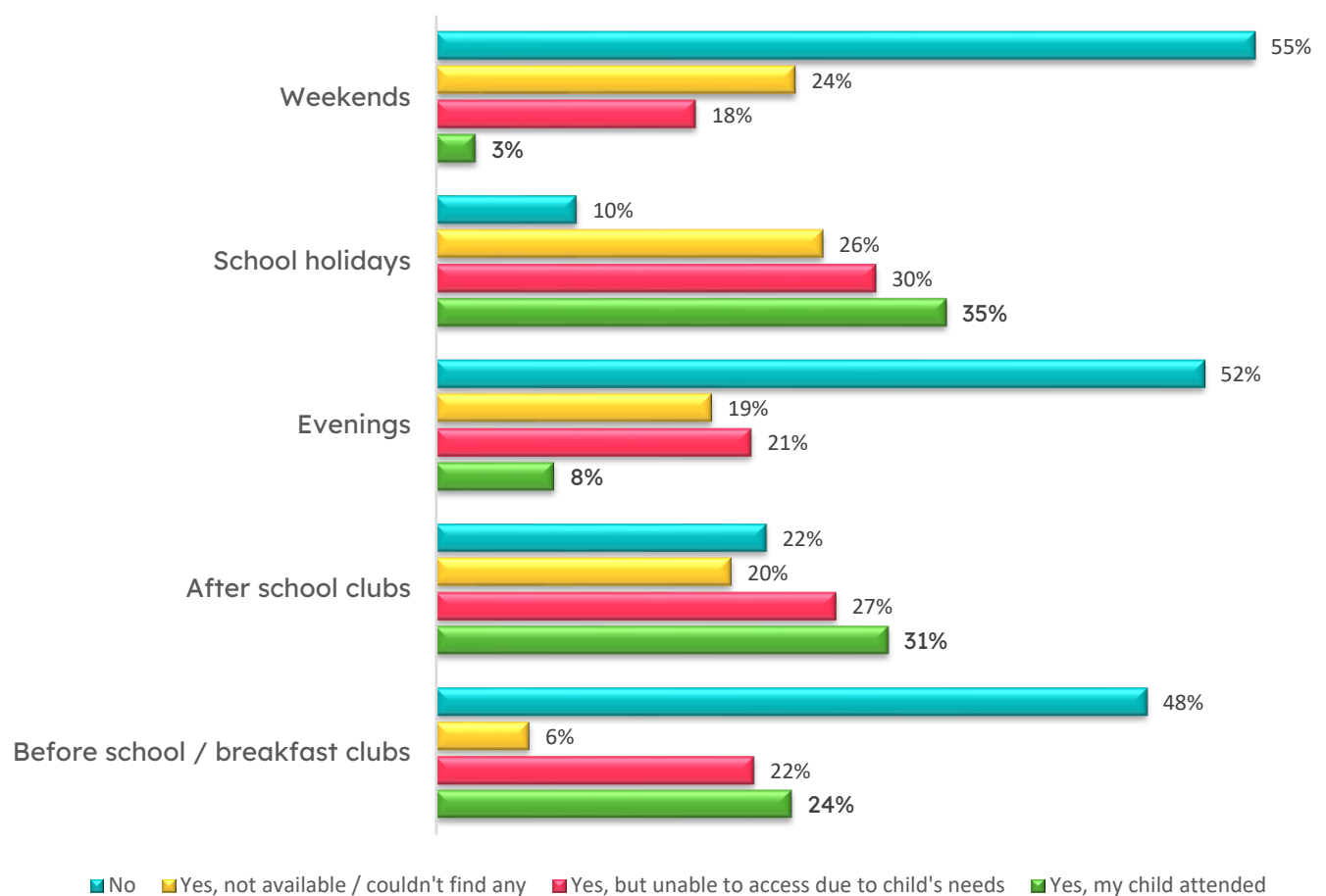
- Our entire household is isolated and depressed
- Struggle to make and keep friends
- I have had to give up work to become a full-time parent/carer due to lack of places for our son to attend during the day
- It would be nice to meet other families who have a baby with special needs

Access to childcare

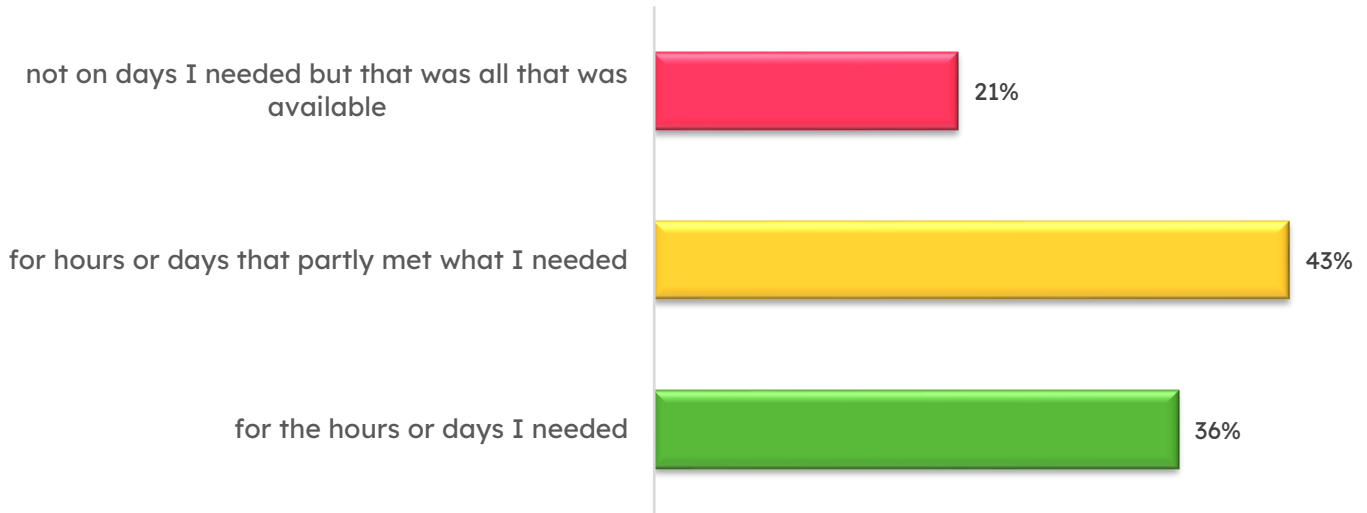
What is your current employment status?



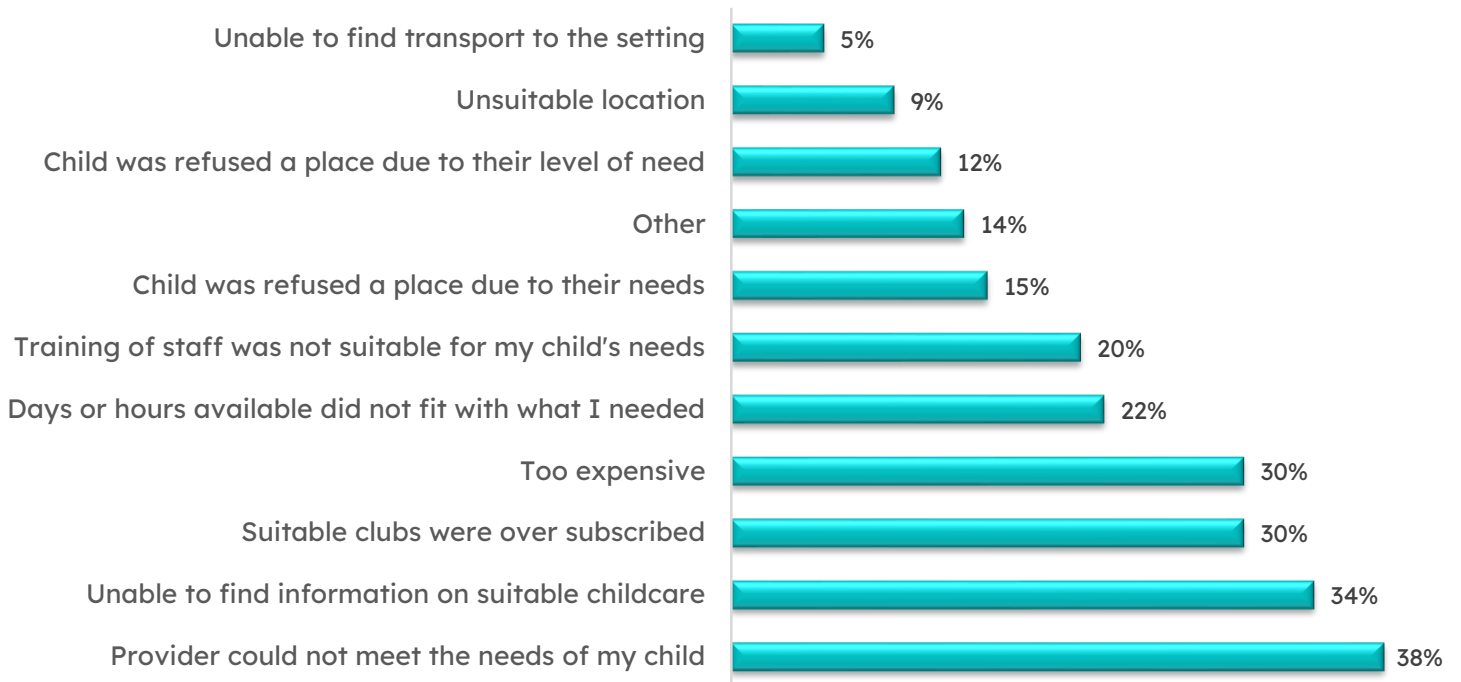
When were you looking for childcare?



If your child was able to access childcare was it?



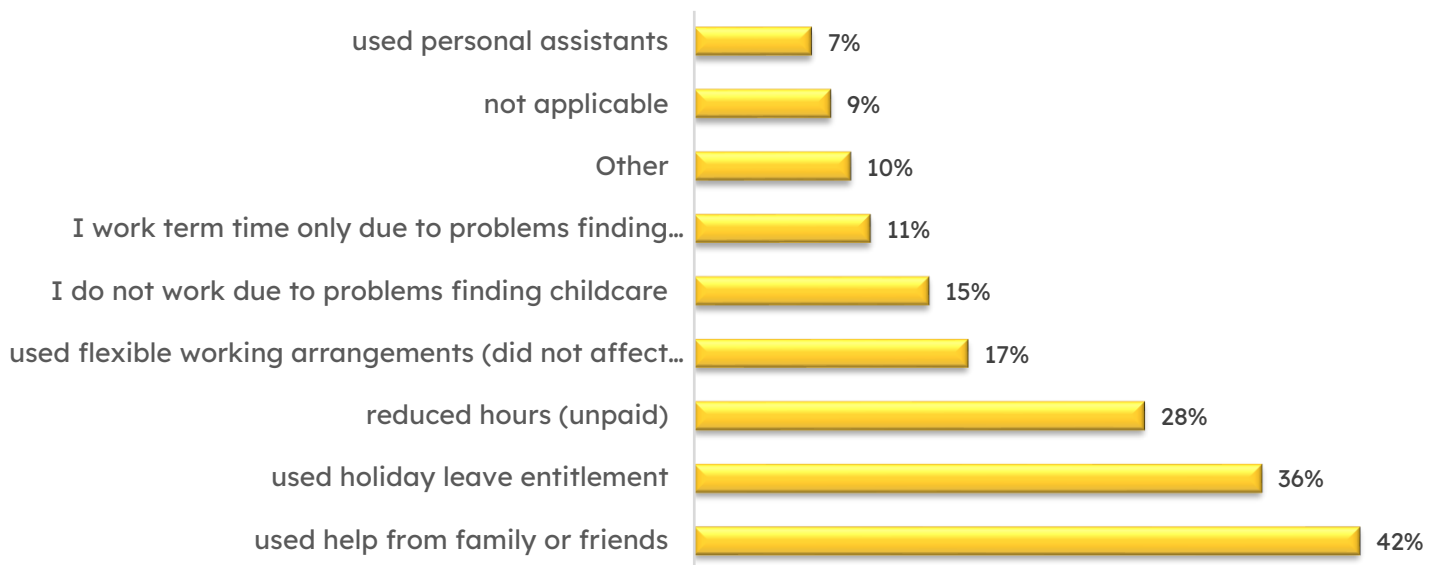
If your child was unable to access childcare was it because?



In the 'Other' category, parent carers said:

- Still on the waiting list for Brandon Playscheme, waiting for funding for mentoring
- Child's mental health
- Hard to find a club which would cater for children with special needs and anxiety
- The childcare we did attend was a play scheme that parents went along to as well
- After school club is ran by school who are trained and aware of my child's needs
- My child is now 19 and most childcare does not cater for their age and level of disability/need
- I was declined spaces to help me out in the summer as we don't get free school meals, so missed out
- My child refused, would run away or root to the spot and refuse to go inside and there was not enough staff to support him to attend
- My children can't cope with a mainstream childcare setting on top of their school day
- There are no suitable clubs available to accommodate additional needs children when both parents are working

If your child was not able to access childcare when you needed it what did you do?

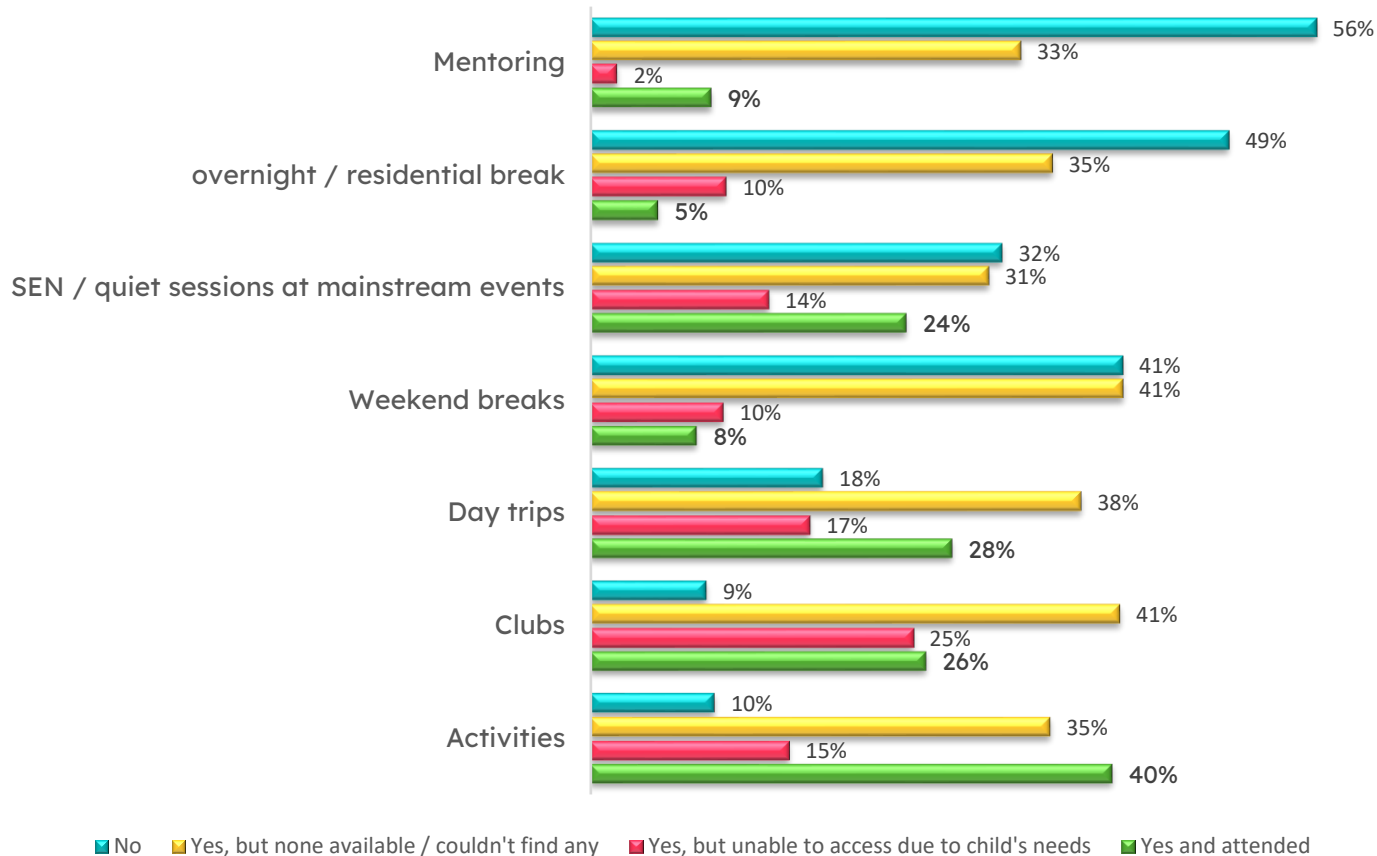


In the 'Other' category, parent carers said:

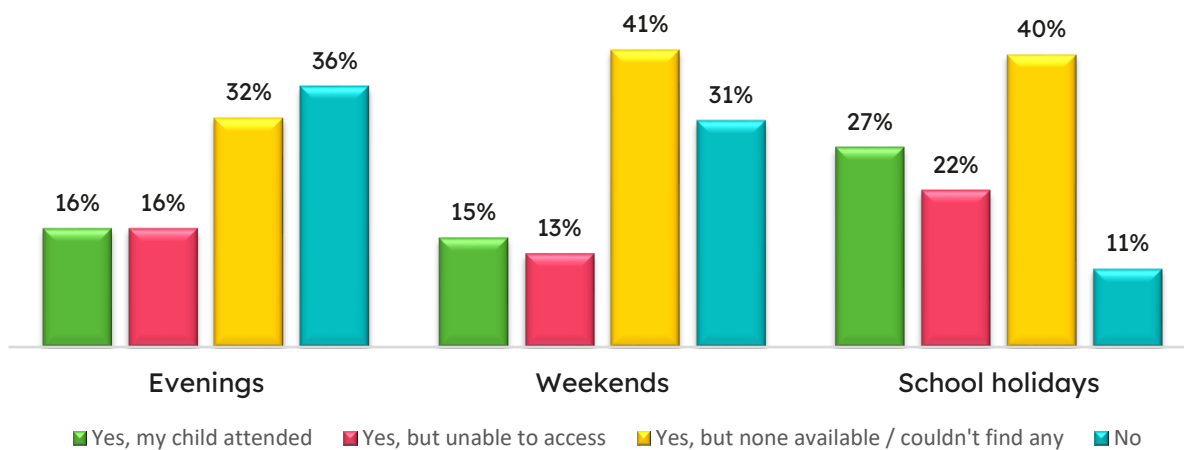
- Cancelled the program/booking/meeting
- Family member sometimes available to help out
- I stopped working to provide care for my child with SEND
- Balanced work and childcare at home
- Changed career
- Had to work and juggle childcare at same time

Access to SEND sessions

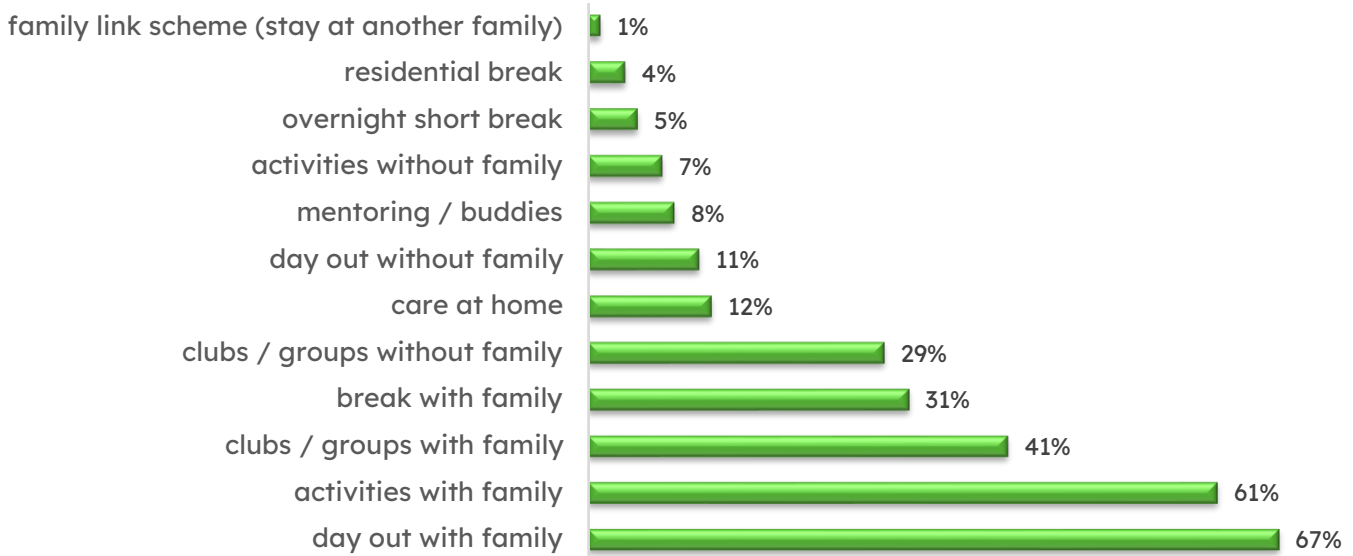
Has your child wanted to access any of the following during the last year?



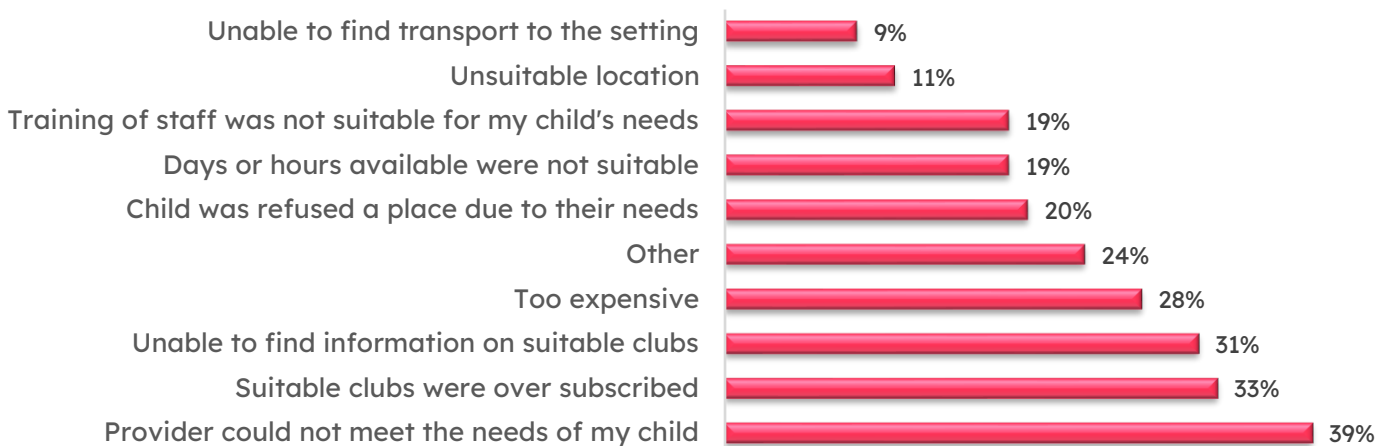
When were you looking for activities?



Was your child able to access any of the following?



If your child was not able to access SEND activities was it because?

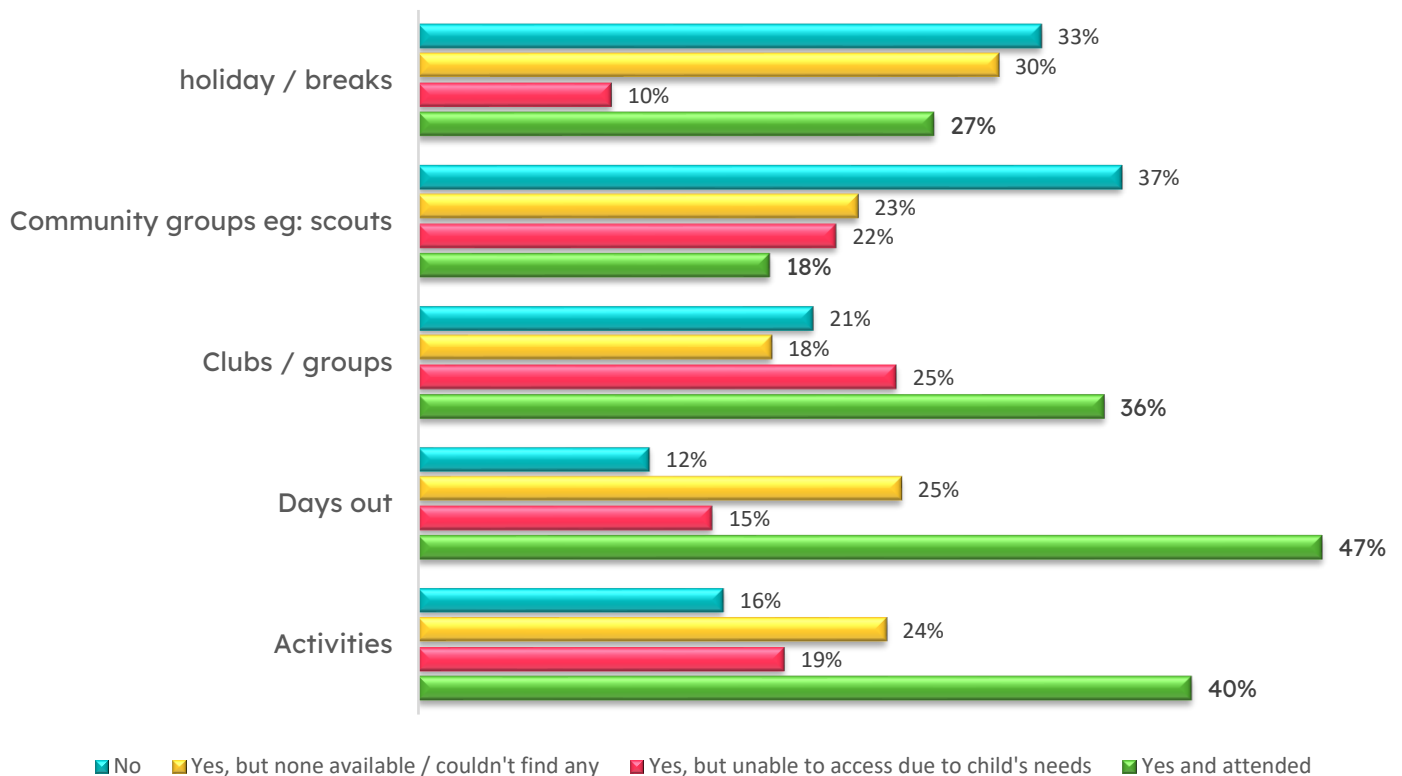


In the 'Other' category, parent carers said:

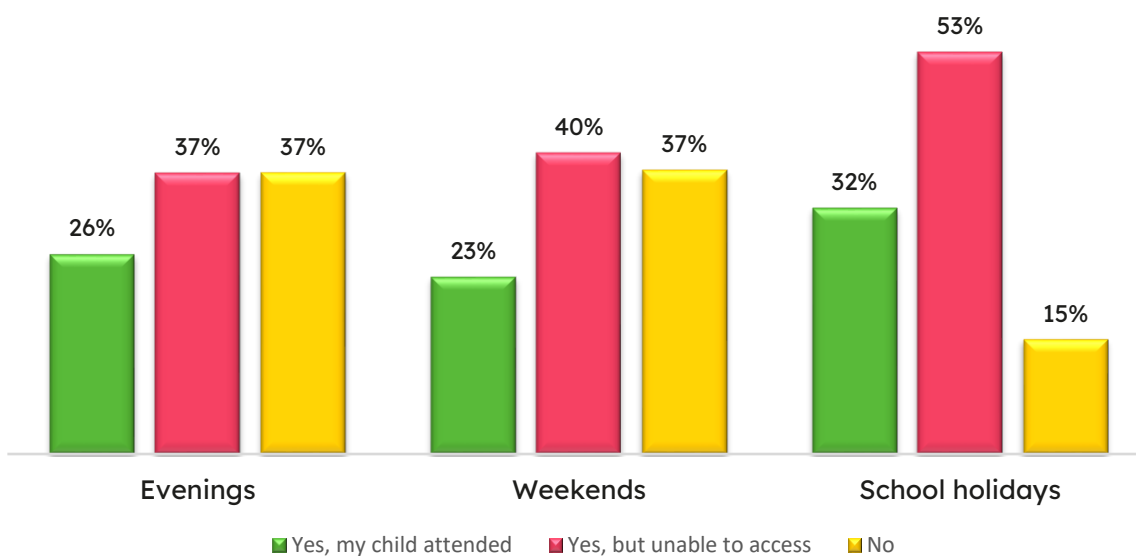
- No staff trained to deal with medical needs
- I was unable to get my child to it due to my other children's needs. They all have differing requirements and needs so it is hard to accommodate their interests individually
- Unable to find anything local
- Not suitable, didn't just want sports clubs, wanted other types of clubs
- Still on waiting lists
- I wasn't aware of any of these places
- We were not sent any information about any clubs or activities for children with SEND
- My child has a physical disability that prevents them from accessing some activities provided like climbing and tennis. There are some activities which are specific to children with a physical disability however priority was not given to these children
- Very limited provision during the day, especially for those classed as NEET
- Many say they are inclusive but then called me after a short time to say he was deregulated. I felt they didn't have the skill to manage autism
- The environment was stressful, too many other children/noise/rules and not familiar/predictable. Or involved physical activity or coordination (both fine or motor) and group participation which is huge area of need so can't access things.
- Not suitable, didn't just want sports clubs, wanted other types of clubs.

Access to community sessions

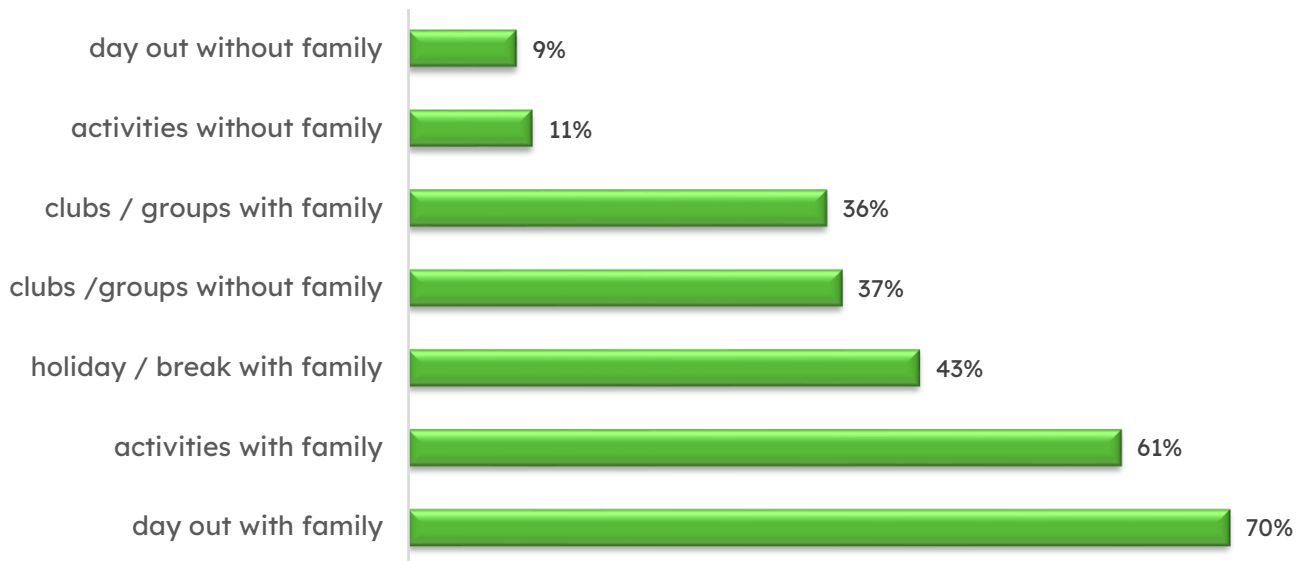
Has your child wanted to access any of the following during the last year?



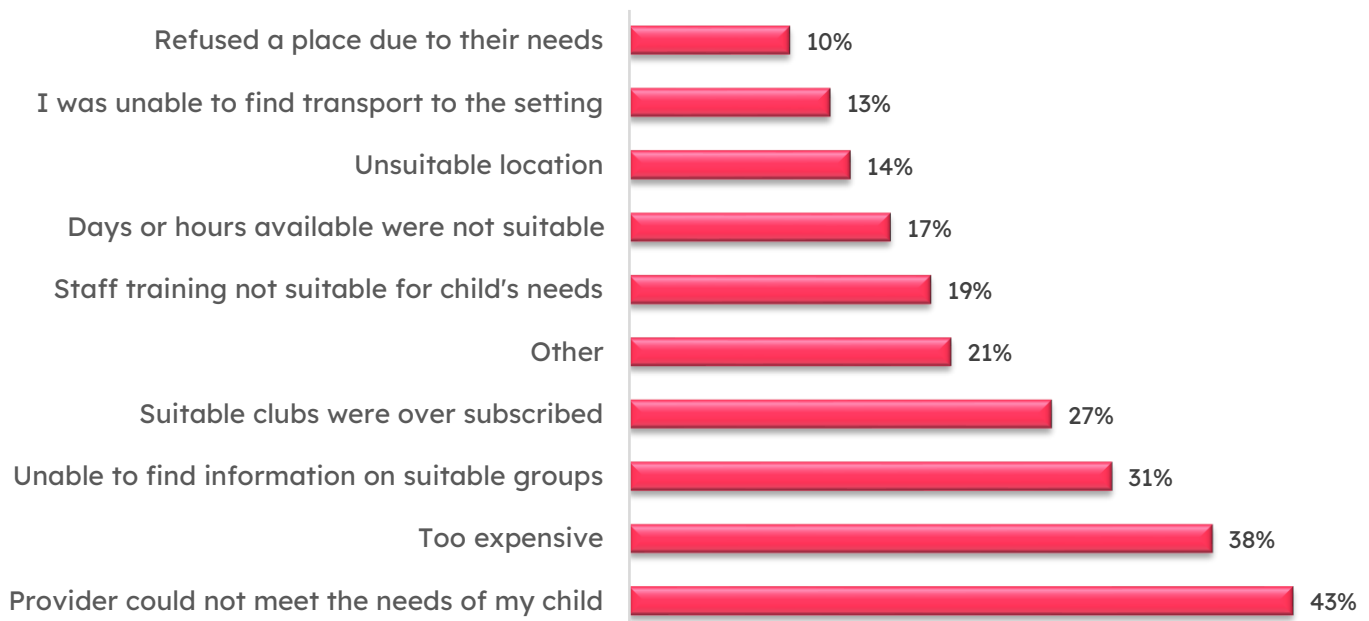
When are you looking for activities and groups etc?



Was your child able to access any of the following?



If your child was not able to access any clubs, activities, days out or community groups was it because?



In the 'Other' category, parent carers said:

- Nothing is wheelchair safe/accessible
- Mental health
- No activities for my child's age group. Everything is geared for younger children

Comments from parent carers

Positive:

- ⇒ So far the school band and a language/cultural visit to Spain. Very much enjoyed belonging to the band with a variety of personalities. Gained a considerable amount of independence from visit to Spain and first night away from home.
- ⇒ Have accessed days out and activities through National Autistic Society and Jigsaw. Both are great, but would like more.
- ⇒ Holiday club attended through JAG at Bradley Stoke leisure centre. Only feasible due to the HAF programme meaning a free place at the club. Enjoyed for the most part.
- ⇒ Football club at SGS wise campus Filton College, my child enjoyed this and came home filthy but had a great time, was all smiles and it did them good to be with friends and burn off energy. My child also attended squirrels bootcamp and loved being outside in nature to be able to hunt for bugs and toast marshmallows over the fire.
- ⇒ In the school holidays my child goes to Brandon Trust Playlink and always has a good time. They also had the opportunity to go to forest school at Grow Wilder in Frenchay - an extremely beneficial experience for them as they get to learn some skills and spend time outdoors. However, my child is unable to go on days out with Brandon Trust Playlink as I was told that due to their needs and behaviour, they would need a 2:1 support for a day trip. I have ongoing health difficulties, which means that the school holidays are extremely difficult for me. I would like more help such as overnight respite, as at present no one other than myself and my husband can have our child overnight. However, when we previously had a social worker I was told this could not be considered until they are older.
- ⇒ My children have both attended sessions with Playlink (Brandon Trust) and Special Friends as well as my youngest accessing sibling support with Bristol Creative Therapy Centre. For Playlink it's important my children attend separately as this provides them with respite from each other as well. Playlink understood this and were able to facilitate it. Unfortunately, neither child got a place on the Mojo active sessions which is a real shame as both are very active and this is the sort of activity to keep their interest - particularly my older child who becomes bored quickly at the school/youth centre settings. Special Friends provided us with some lovely opportunities for family days out and the children have the chance to make friends. They were lucky enough to attend a pilot session with Bristol Creative Therapy Centre in the summer holidays which provided them with time away from their sibling, making friends with peers who 'get it', creative and movement therapy and a space where they could be accepted. They have asked repeatedly for this to continue, and I think there is a real gap and a need for more of this.
- ⇒ My child did two activities/days out and thoroughly enjoyed them. He would like to go again next year to similar activities.
- ⇒ This summer, making use of groups like Brandon Trust, Special Friends and Jigsaw, my son has accessed a wide range of activities.
- ⇒ As members of Special Friends Club we can attend activities for the family during holidays. We would not access these days otherwise. Kingswood AIR is a fantastic parent-led rugby team that our child has been attending for the past year.
- ⇒ I generally arrange days out for us and have not used any arranged ones. It always seems too hard to accommodate all of my children's needs. I do not use childcare and gave up my previous job in the NHS to work as an administrator from home as it was too hard to go out to work and to work set shifts. Working from home means I can work when my children are sleeping or at school and am still available to deal with emergencies or when they need me. One of my children recently started attending a club, but it takes a lot of organisation to manage getting them there.

Negative:

- ⇒ There are a lot of clubs, activities and childcare that we simply cannot access as our child needs a 1:1 so the cost is far higher than for most children. They cannot attend before school and after school clubs as they would need a 1:1 which limits work options. Brandon Trust have been great helping to pay some of the costs of attending forest school with a 1:1 but we still pay a lot of the costs as it is so expensive (£40 per week). The Brandon Trust summer holiday sessions were great but not near to us so involved quite a bit of travel. My child really enjoyed them though.
- ⇒ Activities organised by local autism support groups are good but spaces are limited and sell out fast. SEN sessions at many places are at terrible times!! Too early or too late! We have been unable to find any holiday clubs or provisions to help us in school holidays or at weekends. Anywhere suitable is full with long waiting lists. Plus we have the added problem of my child not being interested and wanting just to stay at home gaming.
- ⇒ I didn't know that most of these things exist.
- ⇒ There are very few clubs/respite that can support a full-time wheelchair user requiring hoisting and help with personal care. There is very little for physically disabled as more tends to be for learning difficulties.
- ⇒ I have found it very hard to find suitable support. The local offer is extremely lacking compared to other places. Despite having a Child In Need plan we can't find any help during the term or holidays at the moment despite the plan saying we should. We managed a day a week with Playlink but one of my children could not cope and struggled to attend due to their needs and not having suitably trained staff.
- ⇒ They were only for kids with free lunch. Mainstream school can't cater for my child's needs of holiday club or after school activity.
- ⇒ My child has been able to attend holiday clubs, but they do have to be able to cater to their needs. My child struggled in some settings not wanting to change themselves because they couldn't meet the need with too many children and my child is of an age now when they don't want others to know about their incontinence issues. My child also would clash with other individuals with similarities with their autism and this would make it more difficult for the providers to manage.
- ⇒ We belong to Special Friends Club, however we increasingly find that activities do not reflect the needs of the whole group and many activities exclude people who have mobility impairments. So whilst fully ambulant members can have their pick of all activities, wheelchair users cannot, nor are they given priority on trips such as the willow boat which is designed for people with more complex needs as it is fully accessible.
- ⇒ Children's services say we should use these respite services however the providers are unable to offer a place to my child on the schemes due to their complex needs. Said due to my child's needs the scheme's policies and insurance were such that they could not support them. We have found none willing to take them without extra 1:1 support, but children's services refuse to provide this.
- ⇒ My child is able to attend clubs in theory, but in practice finds them overwhelming. Last year they attended after school club most days but it is too much for them so this school year we have got a nanny. Similarly, they were attending a community group but the noisy environment became overwhelming so they have now quit and is reluctant to join other groups. We used to use holiday clubs to enable me to work and my child was welcomed there but found the change in routine and environment could be overwhelming and therefore would have toilet accidents and also they would mask all day and then release all her tension when she got home. I have now changed my job to term time only so I no longer need holiday clubs. I am worried about when my child goes to secondary school as I will be working and we will need to continue to use a nanny as there doesn't appear to be any after school support at secondary school and my child will be incapable of being at home on her own.

- ⇒ Some clubs are available for children with additional needs but normally requires a lot of travel for appropriate activities as well as family logistical involvement and planning. Very little respite care available - Brandon Trust Playlink is brilliant but is limited to one session per week. No residential respite available. No breakfast or after school care available at the school he attends - if there was, he couldn't access as reliant on school transport timings. The signposted "offer" has very little that is appropriate.
- ⇒ As my children have become teenagers they want to go where their peers go, but they avoid trying in case it is overwhelming. I feel they are stuck between being too disabled for universal groups but not disabled enough for SEND groups due to being high functioning neurodivergent and I'm not sure there is a resolution for that one.
- ⇒ This summer I failed to find any suitable holiday clubs which has severely impacted my mental health. My partner and I had to take all our leave, we are exhausted and if I'm honest a bit depressed. Our child is bored of spending time with us, they enjoy having friends and they have missed socialising. My child is never invited on play dates, presumably as parents aren't sure how to meet their needs. My child attends mainstream school and goes to the after school club 2 days per week. They have been discriminated against by this club. After a parental complaint they insisted my child must only attend for 1 hour as they can't provide 1:1. They cannot evidence having tried any reasonable adjustments even though I have told them simple things like ear defenders, a quiet space, some Lego just for my child etc would make all the difference. This means I have to leave work at 4pm on these days. I work 4 days per week and have no other after school options so I work into the night to catch up. It's not sustainable and I'm isolated, ill and tired all the time. We have no family help locally.
- ⇒ I find clubs for school holidays are so expensive and are usually fully booked. I have to rely on a family friend to watch my children while I go to work.
- ⇒ We are able to use clubs like Special Friends as I am able to support my child to attend, but clubs such as Playscheme, he is unable to attend, as the staff are not trained to meet his needs and they refuse to give him a place.
- ⇒ Can't find any clubs/groups for SEN kids and mainstream clubs she's denied as they can't meet need.
- ⇒ My children all do kickboxing on a Wednesday, my daughter did do Guides but parents would kick off about her taking part in activities or camps away. We did lots of day trips together.
- ⇒ Many places are too busy for my children and also don't seem to cater for disabled children well. Disapproving looks from strangers also impacts us all.
- ⇒ I can't find any clubs/activities/respite that have space and meet the needs of my children. There is nothing I can find for older early teen or enough spaces for children with SEN what I could find was gone instantly.
- ⇒ Both of my kids have additional needs and an EHCP. I have had to change career and work term time only (limiting my career options) in order to cover school holidays as there is not appropriate childcare options for them. I use Jigsaw holiday activities but there are very few other options for us (mainstream childcare is too much for my children on top of the demands of school).

What would 'good' look like?

Within the survey we asked families 'what would good look like?' in the hope of gaining an understanding of what would make a positive impact on a child or young person and their families' lives, and what would help our SEND community thrive. This is a crucial element of moving forward positively in a co-productive way.

- Families were keen for their children and young people to gain key life skills including social skills, independence, problem solving and confidence. It was highlighted that having quieter, calmer, smaller sessions would be of benefit and that having regular sessions with children and young people with similar needs could help to build confidence and social skills.
- Accessibility was raised as an issue that if changed, could help improve families' experiences. These included activities and settings having correct equipment such as changing facilities with a hoist, and considerations for those with mobility impairments or physical disabilities. Also highlighted was the need for availability of groups tailored to different SEND needs including ME/CFS with short sessions and opportunities and facilities available for quiet rest breaks away from the rest of the group.
- It was felt that more spaces need to be available locally. Distance and transport were raised as concerns for families. In addition, many raised cost as a reason for being unable to book spaces on clubs and activities. This was especially so for those whose children and young people require additional support. A number of parent carers asked for more financial support to be available for children with complex needs, for those who require 1:1 support in order to continue with AP provision for example, and support to provide a PA or help at home to go on activities.
- For many, preparation was key. The need for their children and young people to familiarise themselves with activity/event leaders and for social stories and information about the event that will be taking place to be provided in advance.
- The most significant aspect of success for many was a high level of staff training and knowledge in SEND and complex needs. More appropriately-trained mainstream staff with the right skills was key and it was felt that higher staff to child ratios would help support their child or young person to access activities and clubs.
- Many felt places were limited, filled quickly and/or were unaffordable. Many parents and carers asked that activities be available every week or more often through summer holidays and also for school wrap-around care that is accessible for their children and young people. Also highlighted was a lack of awareness of clubs and activities and also difficulties in finding information.
- A number of parent carers said that more groups and activities with adaptations and support for SEND need to be available for teenagers and young adults to help them make friends and gain confidence. Support for SEND children after school at secondary schools in particular was highlighted as an area that could benefit families; when other children are expected to make their own way home and be home alone but SEND children often can't.
- A variety of suggestions was made for the type of activities that would benefit children and young people, either in the hope that they can find a passion or a skill, or in order to cater for a variety of needs ranging from needing to burn off energy to those that may have a more shy and quiet personality.

- Access to more respite care was highlighted by several respondents as being an area that could significantly help families. Respite care that includes: evenings/nights away/day trips which are not limited due to a lack of road sense; longer hours; respite in the area that can take over from the Children's Hospice. This currently stops at age 20, however one parent carer advised that this is under review and that the age limit may be lowered. They felt that there are no suitable respite facilities that can adequately look after a child with a life limiting health condition and who is physically disabled.

In conclusion, a number of participants commented that accessible SEND activities and clubs would enable them to become part of a community of other SEND families, and that they could confidently leave their children with people that understand their children's needs without feeling embarrassed or stressed that no one understands. It would enable families to be together but also for parent carers and siblings to have time away from caring and time to do things that meet their needs too, providing respite and helping the family's mental health as a whole. It would also provide an opportunity for parents to work, as many cited that they had had to change careers/reduce hours/leave paid employment in order to care for their children as no wrap-around support was available to them.

Our families' view of what 'good' short breaks services would look like...





Email: parent.voice@sglospc.org.uk

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