

Family Voice Norfolk Consultation on Childcare Provision for Parent Carers with Children and Young People with SEND

Consultation

Parent carers of children and young people with Special Educational Needs and/or Disabilities (SEND) were consulted via an online survey in August 2019 about childcare provision and how this impacted their desire and/or ability to return to paid employment.

An interim report, focusing on a subsection of the survey questions, was prepared for the Carers Innovation Fund meeting of 30 August. That report is incorporated in the present report.

Background

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

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

What did we learn?

In some ways, the survey asked more questions than it answered, but some points came through very clearly:

- Families with SEND are not a homogeneous group. Each family has a different set of challenges. The needs of the child or young person with SEND, the other stresses on the family, the degree of isolation or support, the expectations and culture of the family and the age, past experience and economic and geographic situations of parent carers are very varied. Families need a child-centred and family-centred approach to suit their own situation. Above all, this requires access to someone who can engage with family members to discuss their specific needs and signpost to services.
- Several families reported that there was less difficulty in accessing childcare when their child was very young and their additional needs were less obvious and/or easier to manage. For many, social opportunities outside school for the child decrease as they grow older, making preparation for adult life and meetings around this (e.g. at a Year 9 EHCP review) much more difficult.
- Many parent carers are so occupied in simply managing the situation they are in that they have little time, space or opportunity to consider what *might* be. Their priority is being able to continue to support and care for their child and they know that their own wellbeing and mental health is vital for this. It is not surprising that more saw suitable childcare as a way to them to keep going than as a way to look outside the family and access the workplace.

The steering group of Family Voice Norfolk is entirely made up of parent carers of children and young people with SEND and we are conscious that there are questions we did not ask but which underlie many of the responses to this survey.

- We did not ask about the effect that lack of childcare for a child or young person with SEND has on siblings and other family relationships, but some respondents touched on this. The difficulties families experience in accessing suitable childcare has wider implications than the wellbeing of the child or parent carers.
- It is not only paid employment that is made more difficult by lack of suitable childcare. These parent carers are also less able to participate in social and voluntary activities. Their voices are less likely to

be heard in e.g. PTA meetings, patient participation groups, and as active representatives of parent carer forums. Isolation and frustration feature in many of the responses to our survey.

Key messages

Childcare provision

- 31% of parent carers who responded have no childcare provision *at all* – no Short Breaks, no extended family or friends to help out.
- A further 25% rely only on Short Breaks for respite care and have no extended family or friends to help.
- Only 3% of parent carers who responded use childminders to look after their child or young person (CYP). 13% have previously used childminders.
- 75% of respondents felt that additional childcare provision was necessary for their own health and well-being, while 62% said that it would allow their CYP to have more social opportunities.
- 58% of parent carers would like additional school provision for their CYP, with 31% saying they would prefer a childminder.
- All parents would look for SEND experience and 85% would look for special SEN training when choosing a childminder.
- 44% of parent carers would not use a childminding service, mainly because they felt that their child was either too old or too young.
- Of those parents who would consider a childminder, 85% of them would like childminding services during the school holidays.
- 7% of the parent carers who responded are home schooling their children. They have no access to Short Breaks and are solely responsible for looking after their child.

Employment and returning to work

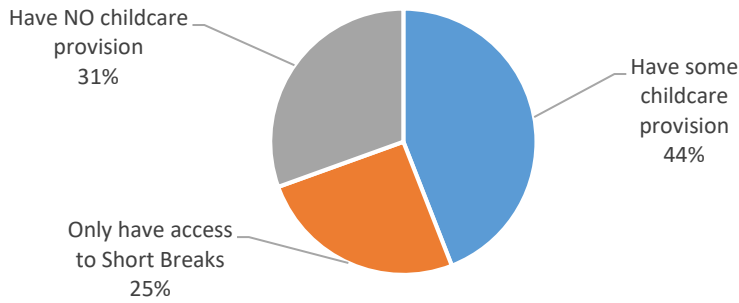
- Three-fifths (60%) of all parent carers said that they had left employment because of caring commitments for their CYP.
- Of the parent carers that had to leave employment to care for their CYP, 88% said it was the additional caring commitment that made them leave, while 32% said inflexible working had contributed and 18% cited an unsympathetic employer. Other reasons given were that it became too stressful to continue working and that they were too fatigued with working and caring for their CYP. School refusal was another reason.
- Nearly 90% of parent carers said that they would like employers to have a greater awareness of caring responsibilities and understanding of how they could support parent carers.
- 67% of parent carers said that support in returning to work did not apply to them as they were either already working or were not looking to return to work.
- Of the other 33%, 58% of these parent carers said that confidence building was the most important attribute to assist them to return to work.
- 27% of parent carers would like to return to work if they could find suitable childcare provision. 35% of parent carers said that they were already working.

Responses in more detail

Childcare provision

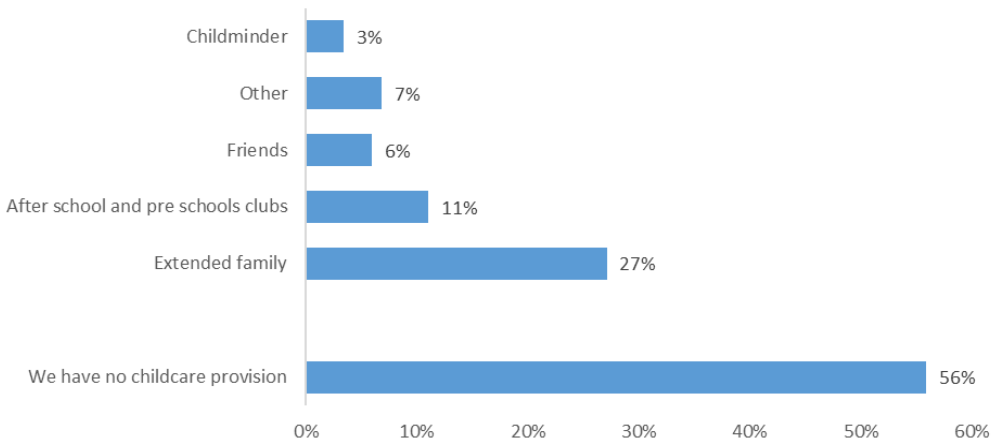
Parent carers were asked if they had any childcare provision in addition to any Short Breaks that they received. 31% have no childcare provision at all. Without Short Breaks, a further 25% would have no childcare provision.

In addition to any Short Breaks provision, what other childcare provision are you currently able to access?



Parent carers were asked, in addition to Short Breaks, what other childcare provision their CYP received. Please note that parent carers were able to choose as many as applied and therefore the total is more than 100%.

Excluding Short Breaks, what other types of childcare provision are available to parent carers



Holiday clubs and nurseries were given as examples for “other”.

Other comments on additional childcare provision highlighted certain recurring themes:

- Most parent carers with children and young people with complex needs rely entirely on Short Breaks for respite as often family and friends are unwilling and/ or unable to look after their children;
- Elderly grandparents and siblings are often the only other carers that children and young people have apart from their parents;
- Parent carers often do not have friends that are willing to look after their children;

- Parent carers do not feel that childminders have sufficient skills to look after their children’s complex needs.

Comments from parents:

“We struggle, as we don’t know anyone who could look after our son who knows/understands SEN. I don’t trust typical babysitters.”

“My older daughter looks after her – that is it.”

“Due to the high needs of the young person (self-harm communication /anxiety) we have no extended family who can look after them.”

“I’m a single mother and had to leave my job as a nurse due to lack of affordable and appropriate childcare options.”

“It’s very hard to find appropriate childcare for an autistic child, they can’t really go on play dates or sleepovers like their peers, there are very few breaks for parents and carers.”

“Our child is medically complex, and have to have a medically trained person to be with her, no family or friends are able to do this.”

Parent carers were asked how having access to additional childcare provision would help with them and their families. Parents were able to choose as many as were applicable.

To improve our health and wellbeing	74.1%
To give social opportunities for child or young person	62.1%
To give us more family time	43.1%
To enable us to socialise	37.9%
To give us more leisure time	32.8%
To support our other caring commitments	29.3%
To attend education / attending courses	28.4%
To return to work	25.9%
To maintain my current work	19.0%
Other	9.5%
I would not use additional care provision	6.9%

Most of the “other” comments related to parent carers being able to spend time together as a couple.

Lack of childcare provision has an effect on the health and wellbeing of parent carers, leading to isolation and crisis. Parent carers wanted more social opportunities for their children or young people and more family time with non-SEND/neuro-typical children.

When asked what provision they would prefer their child or young person to have access to, 56% of parent carers wanted additional school provision, 31% said they would use a childminder and 31% said other options, which included additional Short Breaks including residential respite care, 1:1 support for their child, and holiday clubs.

Parents were asked to give reasons for their choice.

Reasons why additional school provision was chosen

- Consistency of care, especially for children and young people requiring complex medical care;
- Continuation of routine for children and young people;
- Schools already know the children and parent carers can trust the in the level of care.

Reasons why childminder was chosen

- Child or young person already spends a significant amount of time at school;
- Home is seen as a safe and comfortable environment.

Reasons why 'other' was chosen

- Home-schooled children do not have the option of additional school provision;
- Extended childcare provision would allow parent carers to work;
- Young people are too old for childminders.

A full list of parent carers responses is included in appendix B.

Only 16% of the parent carers currently use (3%) or have used childminder services (13%). Some parent carers were pleased with their childminder but the majority felt that the childminder was either unable or unwilling to meet the needs of their child.

Comments from parent carers:

Negative experiences of childminders

“My child struggles to get along with the other children, he needs 1:1 constantly which is not often available, he is a risk to himself and others, despite good relationship with my child and very thorough training in SEN and childcare my childminder finds it difficult to have him with any other children (including her own).”

Positive experiences with childminders

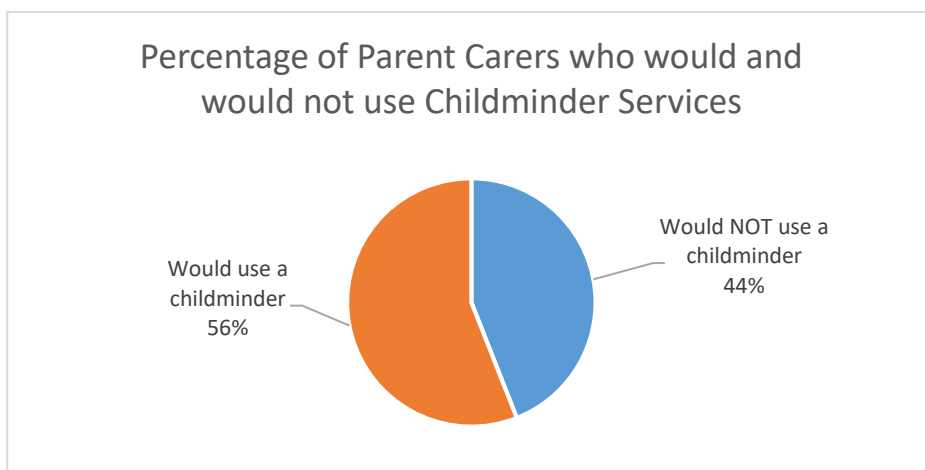
“Prior to moving to Norfolk my childminder had special needs training/experience and was able to cope well with needs. The childminders I have used in Norfolk did not have experience of autism however were willing to support us.”

Refer to appendix C for all parent carer comments on childminders.

When looking for a childminder, unsurprisingly, all parent carers wanted them to have SEND experience and 85% wanted childminders to have special SEN training. 62% of parent carers wanted the childminder to be close to home. 30% wanted back-up cover and 22% wanted the childminder to have enhanced medical training. Parent carers who chose “other” wanted childminders to have DBS checks, have a child-centred approach and to fully understand and accommodate their child’s needs. A couple of parent carers said that they would not consider a childminder for their child.

When looking at accessing activities or support, 78% of parent carers felt it was important for their child or young person to be in familiar surroundings, with 41% saying it was important that they were with friends and 23% being keen for them to meet new people. Parent carers also cited consistency and routine, feeling safe and having fun while doing something interesting.

Parent carers were asked if they would or would not use childminder services.



The cohort of parent carers that would use childminder services said that:

- 82% would use a childminder during the school holidays,
- 48% during term time,
- 51% in the evenings and

- 30% during the day.

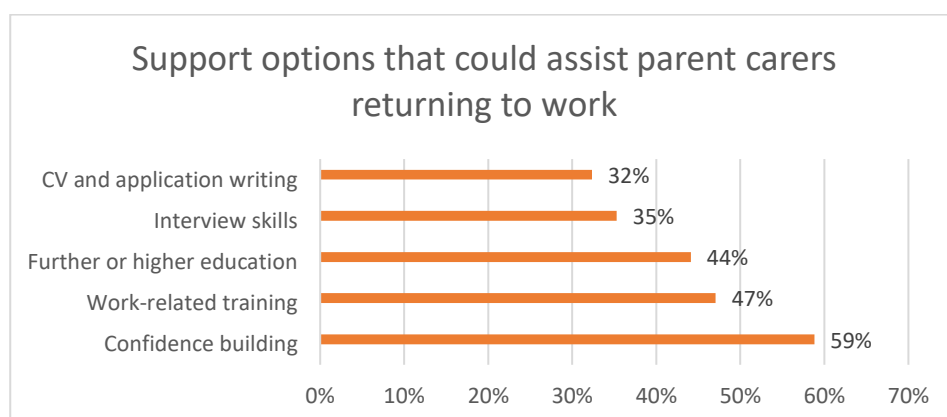
The cohort of parent carers who would NOT use a childminder gave the following reasons (number of responses are in brackets):

- Not confident that the childminder would have the skills or experience (9)
- My child or young person is too old for a childminder (8)
- Stay at home parent, prefer to look after them themselves (7)
- Needs of my child are too complex (6)
- Too expensive (5).

Employment and returning to work

When asked if they would like to return to work but were unable to find suitable provision to meet their child or young person’s needs, 43% of parent carers who responded said yes they would like to or would consider a return to work. 35% are already working. 13% would not consider returning to work (although lack of childcare provision may impact that decision). The other 9% included parent carers who are unable to work due to their own disabilities or caring for their child or young person. Many parent carers said that they could not have a full-time career and worked part-time so that they could still care for their child.

Parent carers were asked what support they would like to assist them in returning to work. Two-thirds of parent carers said that this question did not apply to them as they were either already working or were not looking to return to work. The remaining 33% (34 respondents) said confidence building was the most important support that they could receive. Parent carers were able to choose as many options as they wished.



Nearly 90% of parent carers said that they would like employers to have a greater awareness of caring responsibilities and understanding of how they could support parent carers.

Three-fifths of all parent carers said that they had left employment because of caring commitments for their child or young person. From this cohort, 88% left due to increased caring commitments for their child, 32% cited lack of flexible working and 18% said that an unsympathetic employer meant that they left employment. Other reasons for leaving employment included:

- And caring for sick parents
- Being exhausted due to caring commitments
- Failures in the EHCP process and losing out on transition to a SEN school from mainstream, I've had to quit 3 jobs because professionals fail to follow through with their jobs
- Fostered then adopted. Unable to work in my initial profession once adoption had happened
- Had to leave because of my mental health, could not cope
- My child dropped out of education, he's now returned but needs full on support for meetings etc
- I am disabled myself
- I had flexible working but it wasn't flexible enough – so went freelance

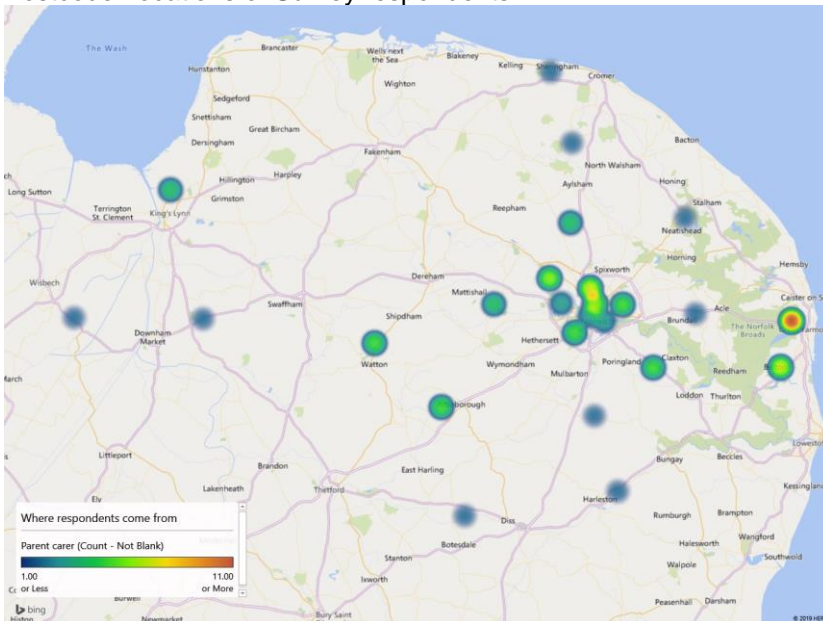
- I left the Royal Air Force during Adoption/ maternity leave when it became clear that my son needed high level care and a military career wouldn't accommodate that commitment.
- Impossible to work due to 3 children with SEN
- No childminder would have our child
- School exclusions and refusal
- Stress caused my carer's fatigue as diagnosed by medical professional
- The stress of my circumstances (and lack of support) impacted upon my health and was not able to be consistent in my job role
- Too many caring responsibilities so couldn't work as well
- Unable to find childcare beyond age 12

Who responded to the survey?

120 parent carers responded to the survey and their responses represent 125 children and young people.

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

Postcode Locations of Survey respondents



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

Final comments from parent carers included:

- Because my child needs 1:1 specialist care it's not been possible to find a childminder who is willing and able to offer this, which is why we have only access to after school clubs for childcare purposes. It would help me to have more access to out of school care for him, but the care he needs is very expensive and might not be covered by my salary.
- More support for working parents
- I am currently working however it is becoming very difficult and effecting my work with phone calls, my mum is the only other person who is able to look after child and she is now exhausted.

Appendix A - Further details from parent carers about the childcare provision that they have.

Comments from parent carers who have Short Breaks

- After school club 2 days a week until 4.45pm
- Charity funded, we have no family support
- Due to the high needs of the young person (self-harm/communication/anxiety) we have no extended family who can look after them.
- Extended family not on our doorstep and involves 70 mile round trip and careful planning, plus they are now elderly grandparents and my child is very full-on
- Family live far away and although our child sometimes goes round friends' houses this is usually for short periods of time. Our child doesn't want to leave us, as they see this as "us trying to get rid of them"
- How can SEN children develop social skills when there is little provision for them to be looked after. Everything I attend with my child I have to stay.
- I have no choice but to place my child for the minimal amount of time possible in an inappropriate mainstream provision as Short Breaks will not fund a PA.
- I'm a single mother and had to leave my job as a nurse due to lack of affordable and appropriate childcare options.
- It's hard to find a child minder that has capacity or are trained appropriately.
- It's very hard to find appropriate childcare for an autistic child, they can't really go on play dates or sleepovers like their peers, there are very few breaks for parents and carers.
- My mum will take our child infrequently and for a maximum of 3 hours at a time as my child overwhelms her.
My in-laws will take our child for about 4 hours but this is very infrequent as they live a long way away.
- My son has 1 to 1 at school and apart from that, he is with me or husband who works a variety of long shifts. Family live over 300 miles away and former friends distance my son from their children.
- No one is able to look after our children as no one can cope with them!
- Not many people are willing to take responsibility for my child for any length of time.
- Our child is medically complex, and have to have a medically trained person to be with her, no family or friends are able to do this.
- Our son sees his grandparents regularly but only stays with them on the odd occasion. They sometimes pick him up from school but this is not a regular occurrence. His has recently stayed with his Auntie but again this is not a regular occurrence...the last time was 5 years ago!
- Sadly we have no childcare provision and are at breaking point
- This answer refers to my sister - who can cope with him for a few hours at home (evening hours)
- We struggle, as we do not know anyone who could look after our son who knows/understands SEN. I do not trust typical babysitters.
- We used to use my mother in Kent for help. Unfortunately, now we have moved to Norfolk we no longer get support. My mum is highly trained and understands his severe complex needs

Comments from parent carers who DO NOT have Short Breaks

- 2 years without proper education or socialisation. We are not able to get short breaks. Child has SEN.
- Dad (we are divorced) cares on Wednesday nights and alternate weekends.
- I cannot find anything appropriate.

- I currently only have my mum who I feel is able to look after and care for child due to challenging behaviour. I also work full-time however it is now becoming exhausting for her. She also looks after child whilst I am at work (I work full time as a nurse), we also have to be on standby in case we are required when child is at school
- I don't have anyone else that helps me.
- I have lost some of my income due to my son being discriminated against by his childcare provider and am at risk of losing my job completely if this is not resolved in the next few weeks. The provider's discriminatory attitude towards my son is destroying me. I've had to pay extortionate amounts of money to a solicitor just to try and keep my job. The whole system is just despicable and it's awful that childcare providers, schools, and local authorities are getting away with this. Depriving hard working parent carers of access to childcare has a much wider impact on society as well. I've had time off work sick (partly due to the stress of my childcare situation) and my colleagues were left covering for me for months, so it impacted on them as well. If I lose my job because of lack of childcare, my employer will be losing an experienced member of the team. I think the lack of childcare for disabled children, and the fact that providers get away with severe and protracted discrimination, speaks volumes about the kind of society that we live in. Something needs to be done about this urgently!!
- I have one friend who can babysit if both of my children are already in bed. I have no one able to take the children in the daytime or if they are awake due to significant and complex needs of my youngest.
- It is very stressful not being able to have someone help look after my young person, I have no family to help and cannot find anyone to help.
- My child lives in total isolation
- My older daughter looks after her – that is it.
- My parents help where they can, however they are elderly and not in good health.
- Our parent (ex)friends have excluded our children from the circle
- Rarely able to have a break despite all services knowing I have been unable to cope. Only rarely get a few hours break and during that time I am anxious as I know my mum can't manage our son's anxieties/behaviours/needs
- Single mum with no local family
- My husband has had to give up work as we had no support to offer alternative options.
- Not allowed at wrap-around care due to needs
- We don't need it as I am a full-time mum at home and a carer for my son

Reasons why only Additional School Provision was chosen

- Access other activities through school
- I have never used a child minder. I prefer a nursery setting.
- I would like for my son to be able to do more sports clubs and things that focus on his independence skills
- If I manage to secure my daughter our choice of complex needs school they also offer residential breaks in the holidays. I feel this would benefit us both some respite care for me but also an experience for her in the form of a "sleep over" or "play date" two things that she doesn't experience at home as she's never invited to parties or gatherings.
- It would be great for flexibility for when something delays me from pick up.
- My child is a teenager and extra-curricular clubs add social skills and independence. Also if clubs are about sports - helps with health and well-being.
- My son goes to complex needs school and there is no breakfast or after school clubs
- My son is 2 years behind at school and is in need to support
- My son is older
- Our granddaughter is very sociable, and attends a brilliant school, so more contact with her peers in a supportive environment would be good for her.
- School is currently not able to provide level of one to one care my child really needs in order to progress
- School know him best
- Setting they are already familiar with
- That is where he is most comfortable
- Trusted source
- We cannot have too many different people performing the medical procedures on our child.

Reasons why only Childminder was chosen

- Advance level support for my son. Must understand epilepsy and emergency medicine
- As Mum and Dad we are 'cringy'. Our son needs a PA who is younger and he can relate to.
- Child is happier in a "home" setting.
- He is already at school a lot, he needs to socialise outside of school
- Home environment
- I would like her to be in a home from home environment.
- My son doesn't like school so would see extra school provision as a personal punishment which would result in increasingly violent behaviour.
- My son prefers being at home to school so wouldn't be keen on staying longer at school to access activities. Prefer support at home in his safe environment.
- Our son's school is great; it's at home where we struggle
- To allow me to do things with my friends other children at weekends
- To get a break
- Current summer clubs over-subscribed and for those with high needs (very expensive!)

Reasons why Additional School Provision AND Childminder was chosen

- I would be happy for my children to be with a childminder or additional school provision if they found it appropriate and could receive the right level of care.
- My child have limited social interactions and friendship grounds.
- My son adores his school and struggles in holidays without the routine.
- School is difficult and still awaiting EHCP so no funding currently there, child has extra support in school however these are different people on different days. At home someone to assist with childcare would be amazing to do thing with my other child that we are currently unable to do.
- School provision would mean child is familiar with environment and staff. However a childminder would provide a safe home environment with opportunities for child to socialise with neuro-typical children
- The school are experienced and a specialist childminder could be considered
- Flexibility
- Greater opportunity for SEN childminder facilities would enable both of us to work

Reasons why Other was chosen

- I desperately need respite and as there is no appropriate school provision for her in Norfolk. We have to home educate So additional school provision isn't an option.
- Probably more opportunities for different interests
- We are all very socially isolated and would use provision wherever we could get it.
- We don't spend enough time together with our daughter. We also both like to run and cycle but can't enter running events together or go on a bike ride together. We also hardly ever go out together as a couple.
- Wrap around care and holiday clubs are useful to allow me to continue working. The option for occasional weekend care would be useful for odd occasions to get out of the house/do something for myself and with my older child.
- My child gets upset by attending extra school etc. as they feel we don't want them. This isn't true at all but we are balancing work (we have both had to go part-time, but have demanding jobs) with family life.
- Child is now 16, childminder inappropriate and school provision not available in our area for child's needs
- He would love to pursue free running, guitar lessons, have more ski lessons to enable his special Olympics career.
- I want my child to have opportunities to socialise and meet new people and do interesting things.
- Long travel/school days prevent evening clubs and not enough of range of activities and not enough central Norfolk/Norwich/South.
- My husband and I need to spend quality time together, to recharge our batteries.
- My child is unable to socialise or access activities without support.
- My daughter struggles with new people I'd be more stressed sending her off with strangers.
- They have not had any time away from us. They socialise with no one but is.
- They know my child well and he enjoys going. I feel happy to leave him.
- They would be able to build a relationship and engage in activities that would not be offers in school or by a childminder.
- To provide better care to alleviate his anxiety of there being unfamiliarity and older children
- We desperately need more than 6 nights a year as we are struggling

Experiences of parents who have used childminders

Negative experiences

- Childminder does not recognise 'labels'
- It stopped abruptly for my daughter when she went to high school and actually I think the childminder just wanted an opportunity to stop it. When my daughter was easy for her it went well, but when there were issues soiling etc. I'd have to go early and get her.
- My child struggles to get along with the other children, he needs 1:1 constantly which is not often available, he is a risk to himself and others, despite good relationship with my child and very thorough training in SEN and childcare my childminder finds it difficult to have him with any other children (including her own).
- Nightmare
- Terrible. My son was rejected after the childminders who had looked after him for 2 years decided he needed more discipline. The last childminder I met with said they couldn't meet my child's needs and when I told my child he wouldn't be going to her he punched me several times in the nose. I couldn't face trying again and had to give up work.
- They found my child a bit of a challenge
- Used a childminder as a one off but she wasn't very good (don't wish to name her). My son came home distressed.

Both negative and positive experiences

- Not for our granddaughter but for one of our great grandchildren (who is 2). She has been excellent.

Positive experiences

- Good - experienced childminder was first to push me into getting a diagnosis
- Many years ago when children were young before they were at full time school. it worked well for us at the time, our daughter's additional needs weren't so obvious when she was small.
- Our childminder is brilliant with our son
- Prior to moving to Norfolk my childminder had special needs training/experience and was able to cope well with needs. The childminders I have used in Norfolk did not have experience of autism however were willing to support us. Childminders advertise that take children up to age 12 - a disability does not stop at that age so it is difficult to find appropriate childcare for an older child.
- We used a local childminder when I used to work longer hours. She was very good and both our children loved her.
- When my child was younger
- When my son was preschool age. Child minder was great.
- When the children were very little but they are now 10-13

Other comments from parents who have not used childminders

- His needs are too complex.
- Nobody would take needs 1:1
- At this time, my child needs our parental direct support due to early years trauma / attachment needs / SEN. Childminding and after school is not positive for my child at this time, maybe in a few years' time.