

Short Breaks and Respite for Children with Disabilities Results of Engagement April / May 2023

Introduction

We wanted to hear the views of families, staff and other professionals on the future shape of the way short breaks are provided for children with disabilities so began a 6-week engagement campaign which took place from 18th April to 29th May 2023. The engagement was able to capture the views of 233 people from an electronic survey and 6 focus groups. This report looks at all 233 responses.

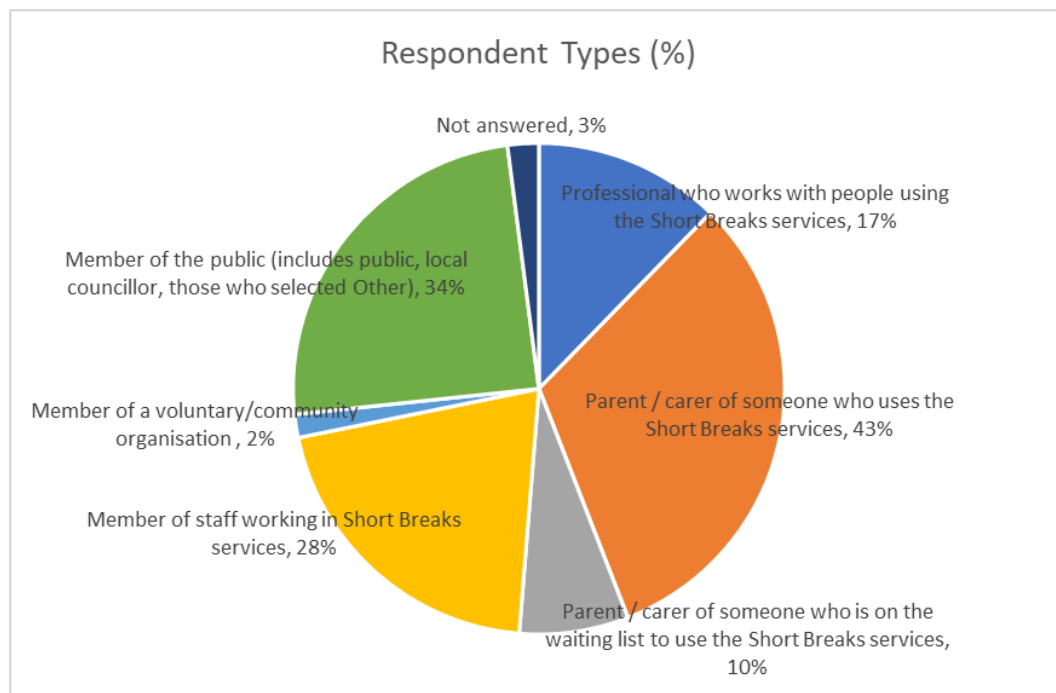
The electronic survey received 195 responses, 126 fully complete and 69 partially complete. 38 people attended the focus groups, 25 short breaks staff, 7 parents/carers and 6 practitioners.

Of the 6 focus groups 3 focus groups were with current provider staff and 3 were a mix of practitioners and parents / carers. 2 focus groups took place in Northampton, 1 in Kettering, 1 in Wellingborough and 1 in Rushden plus one virtual group. There was a range of different times and days to try and make sessions as accessible as possible.

Electronic Survey Results

Respondent Information

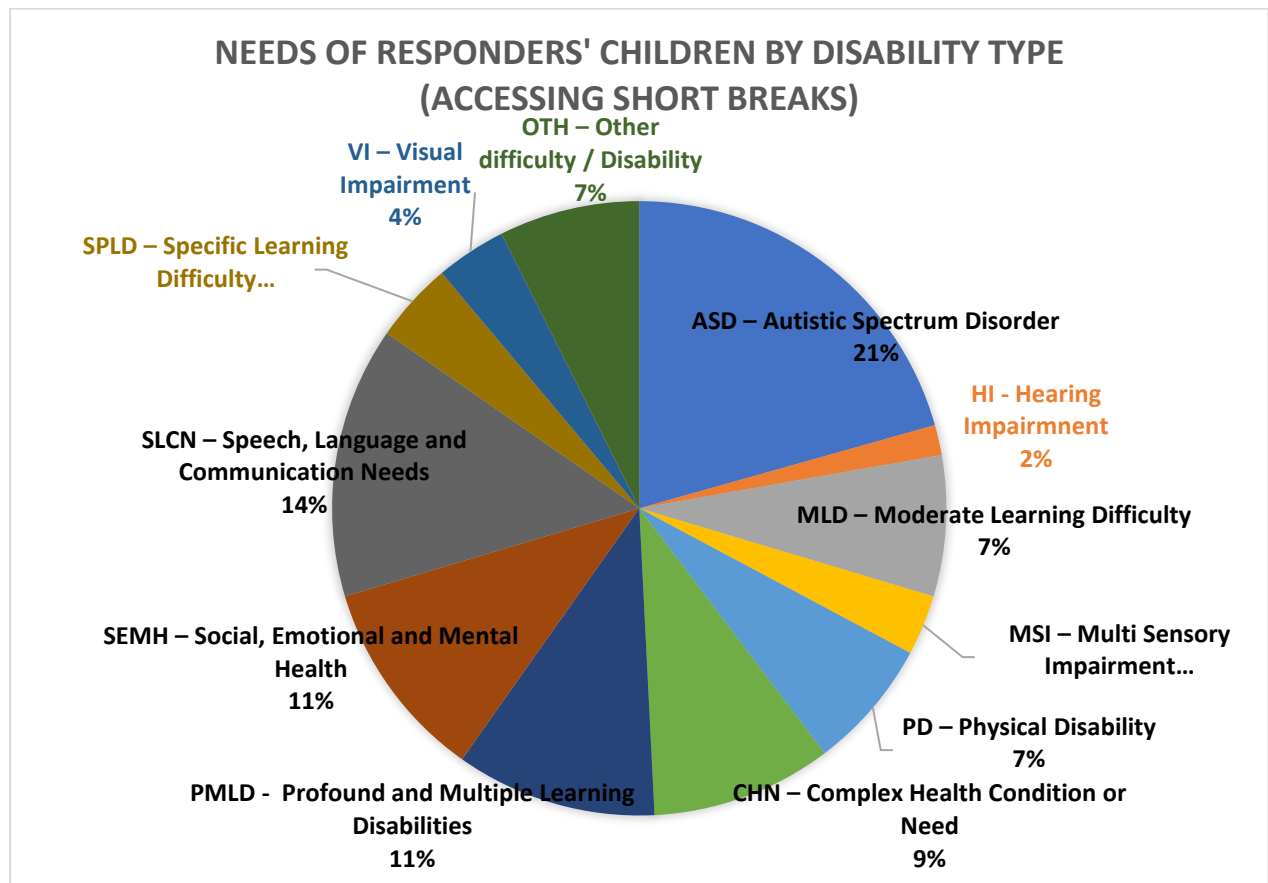
The majority of responses were from parents/carers of someone who uses the Short Breaks services (43%). This was followed by members of the public which made up 34% and staff working in Short Breaks services at 28%.



Child Information

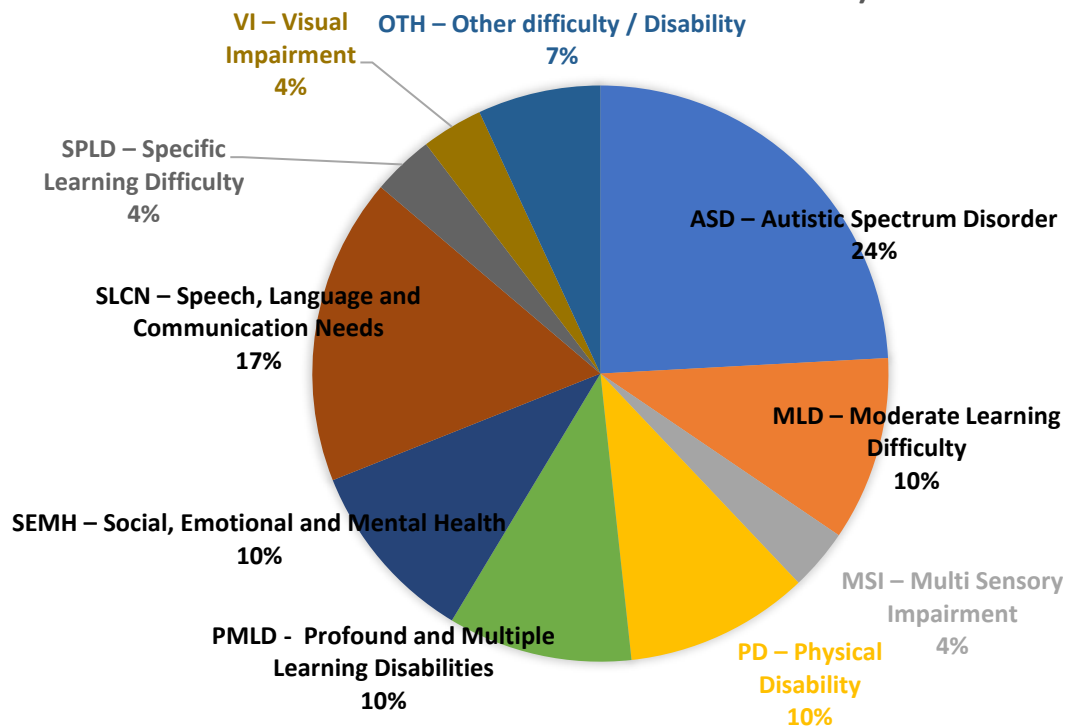
The majority of parents responding to the survey had one child with a disability. The largest age group was young people who were 16 years old.

The highest disability type for children of the responders who access short breaks services was Autism Spectrum Disorder (ASD) at 21%, followed by Speech, Language and Communication Needs (SLCN) at 14%.



Parents / carer's children who are on the waiting list were very similar to the responders' children who were accessing short breaks, with the two highest disabilities being 24% of children who were Autistic and 17% having a speech, language or communication need.

NEEDS OF RESPONDERS' CHILDREN BY DISABILITY TYPE (ON WAITING LIST FOR SHORT BREAKS)



Personal Care / 1:1 Staffing Needs

72% of responders' children required either personal care or 1:1 support.

Access information

Most of the respondents accessed either non-residential short breaks services (35.5%) or attended residential short breaks at John Greenwood Shipman (JGS 35.5%). 12% were waiting to access a service.

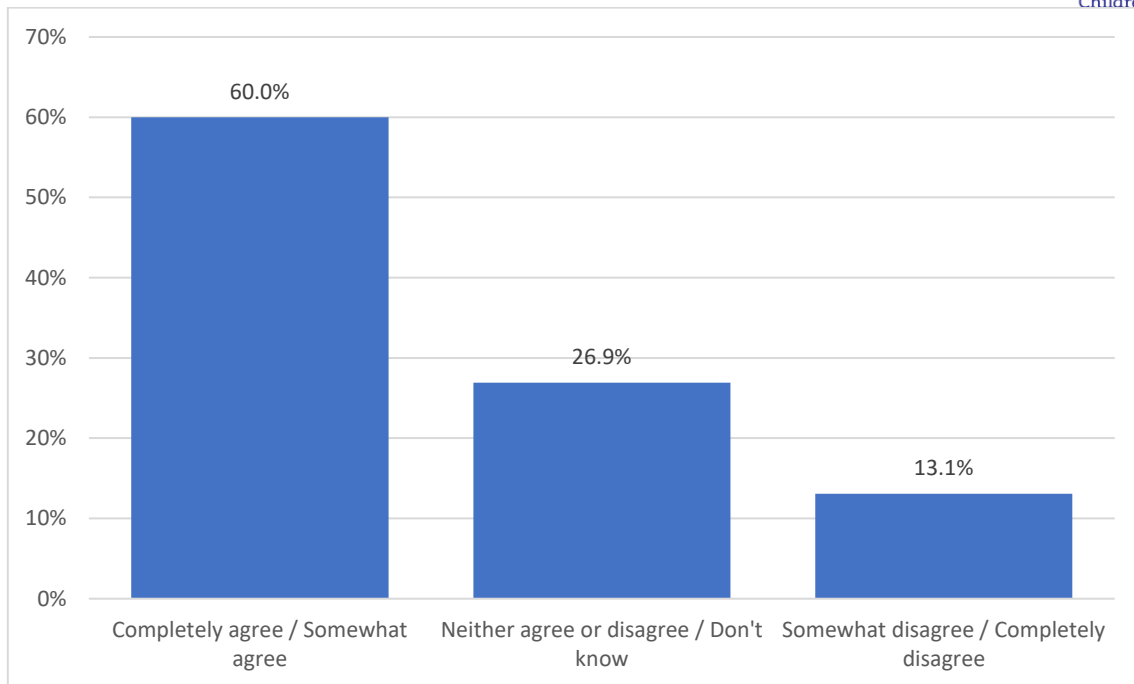
For the non-residential short breaks services most respondents attended Fernie Fields in Northampton, Daventry was the second most attended and third most attended was the commissioned service at Greenpatch in Kettering.

Other community services attended were non-commissioned Greenpatch (23%) and The Cube Disability (15%).

Activities attended were holiday clubs (28%), sports activities (15%) and arts and crafts (5%).

The Survey Questions

1. To what extent do you agree / disagree with bringing residential and non-residential short breaks services together to support the needs of children with disabilities?



60% of responses completely or somewhat agreed that residential and non-residential services should be brought together to support the needs of children and families. Those agreeing the most were Parents / Carers who had children on the waiting list and members of the public. The majority of staff either did not know or neither agreed nor disagreed. 130 people answered this question.

Some parents said there are currently not enough services to access so it would be invaluable if this meant additional services, more intervention and access to support earlier. Parents said that although they are sceptical, the current model doesn't work so they are open to change. There is the emphasis for a variety of providers, opportunities and choice needed. Some parents said that a joined-up service would be great if it was more flexible and met the needs of the child and family whilst also avoiding repeating information and form filling which families don't have time for. There was a concern that overnight short breaks would be reduced to fund other services and the quality of services will be decreased if it is combined. Some comments said that equitable access is very important and all families should be considered and assessed, it is currently very disjointed and overwhelming for families.

There were also comments that this question was ambiguous, and their response would depend on how the model is accessed and implemented.

Focus Group Feedback

Parents generally felt that it was a good idea but only as long as the Provider could deliver the model and manage the staff to a high standard of service. They wanted to be sure that the new Provider should understand the range of needs and complexities that the children accessing the service have.

Parents and staff both had concerns about the budget staying the same and wanted to know how the new model would be achieved within budget.

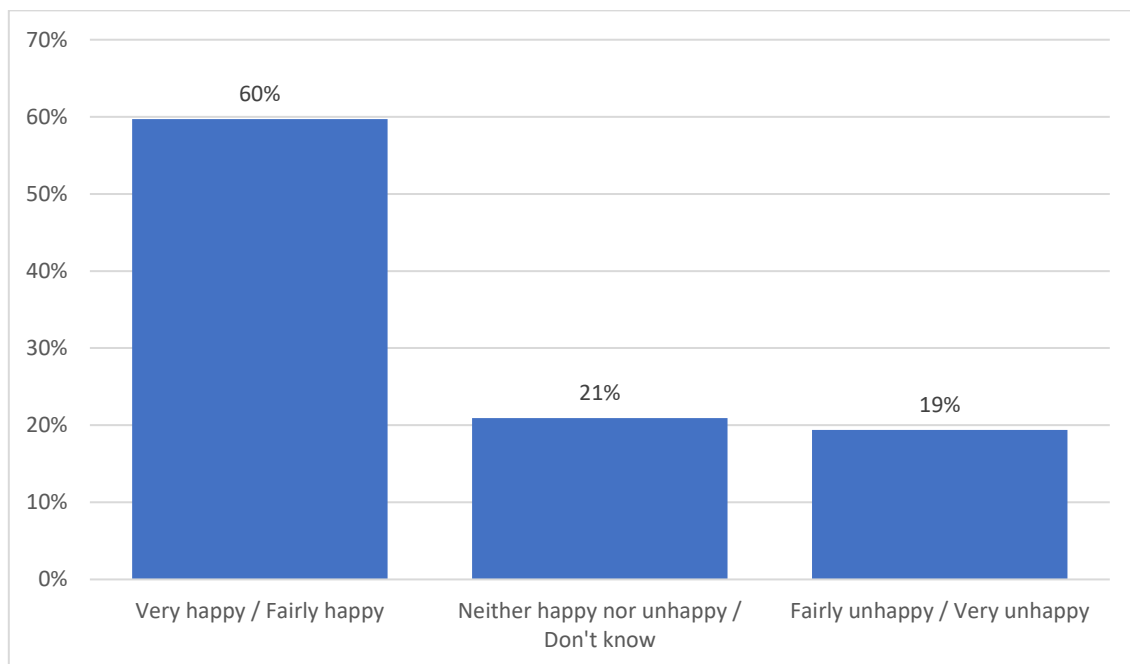
Staff had questions about how the services would be affected and how it would work such as; how long the contract will be, who could be potential providers, how will a cross county service work

with two separate unitaries. They said that it is unsettling going through this but said it did feel different to before. Staff did start identifying potential opportunities on how to join up and how to use premises / staff differently such as running non-residential groups in residential short breaks centres.

All parents and staff wanted to be regularly consulted throughout the process so that they could keep up to date. Parents wanted an ongoing forum or focus group to monitor progress.

There was generally an agreement from parents and staff that the idea of joining the services with one lead provider was a good idea in principle but were tentative about how well it would be executed in practice.

2. How would you feel about a staff team that could flex support across residential and non residential short breaks and potentially also support in the home?



60% of responses were very or fairly happy with a flexible staff team. The majority of each of the groups were very or fairly happy except Staff where the majority were very or fairly unhappy. 129 people answered this question.

Some parents say this makes sense as providing continuity of care across settings can be beneficial to ensuring that knowledgeable staff are caring for their child, with a staff team they have built a relationship with. Some parents were concerned about the training and quality of the staff, as the staff in residential short breaks are more highly trained compared to staff in other services.

Many are positive about bringing staff together and say it will help their child to feel less anxious in new environments if they know the staff around them. Some staff working in short breaks commented that they are happy in their current role and would not want to work in different environments such as in families' homes.

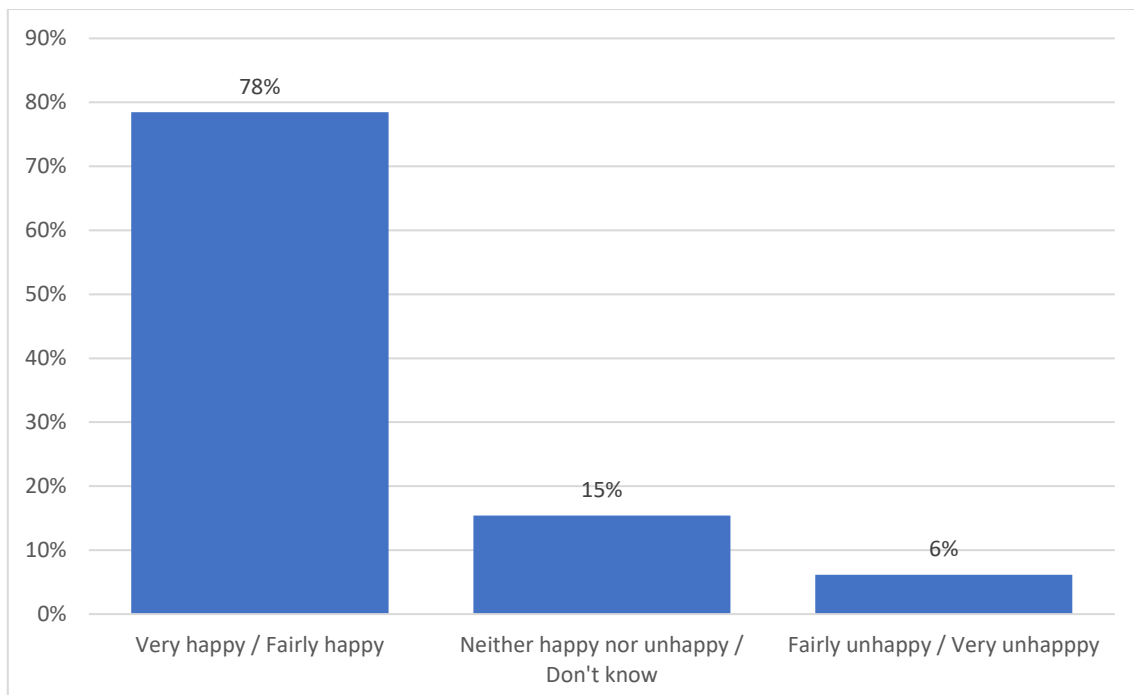
Focus Group response

Staff had more concerns about this question than parents did, but they could see the pros and cons of this approach. Questions from staff were about how their current contracts and working practice would be affected as well as Ofsted registration and the nursing staff for the residential short breaks. They liked the theory of the model but were tentative about how it would work in practice. They could see the potential to improve staff cover for annual leave and sickness absence and more opportunities to increase skills and knowledge and also working hours for those who wanted more hours. They could also see potential to be able increase opportunities to recruit apprentices and have student placements.

Concerns about the impact on families were two-fold, the positive being that children with 1:1 staffing needs could have better support to access non residential short breaks and that there could be a consistent approach of supporting children across all services. However, they also felt that children who like consistency of approach could be affected if there are too many staff changes.

The staff started to think about potential opportunities and ways to manage this such as copying what RSB do with their newsletters by having a focus on a different member of staff so that parents can get to know them a bit more. Having more opportunities for staff to be PAs for parents when they have a Direct Payment and what opportunities there would be around personal care and support services (whether they were part of the budget?). Whether the joined-up staff approach could widen out to other staff such as community nurses and behavioural teams to improve the multi-agency joint working. Finally, they felt that there would be more opportunities to build links with community services.

3. How would you feel about one referral point and joined up assessment and reviews for all of the short breaks services?



People were overwhelmingly in agreement with one referral point and joined up assessment and reviews for all short breaks services, 78% (102). 130 people answered this question.

Parents said that not having to repeatedly tell their story and child's needs to professionals would be hugely beneficial. The current system is very complicated and the simpler and more direct the better. One comment stated that a danger of one referral point means that it may be missed by families not aware. There was also a comment around data sharing and one parent made the point that they only wish to share their personal data with the service that their child is accessing.

Another point that was raised in the survey and focus groups, is that having one referral point will create a bottleneck for these services, leading to an even longer waiting time and higher criteria.

Focus Group response

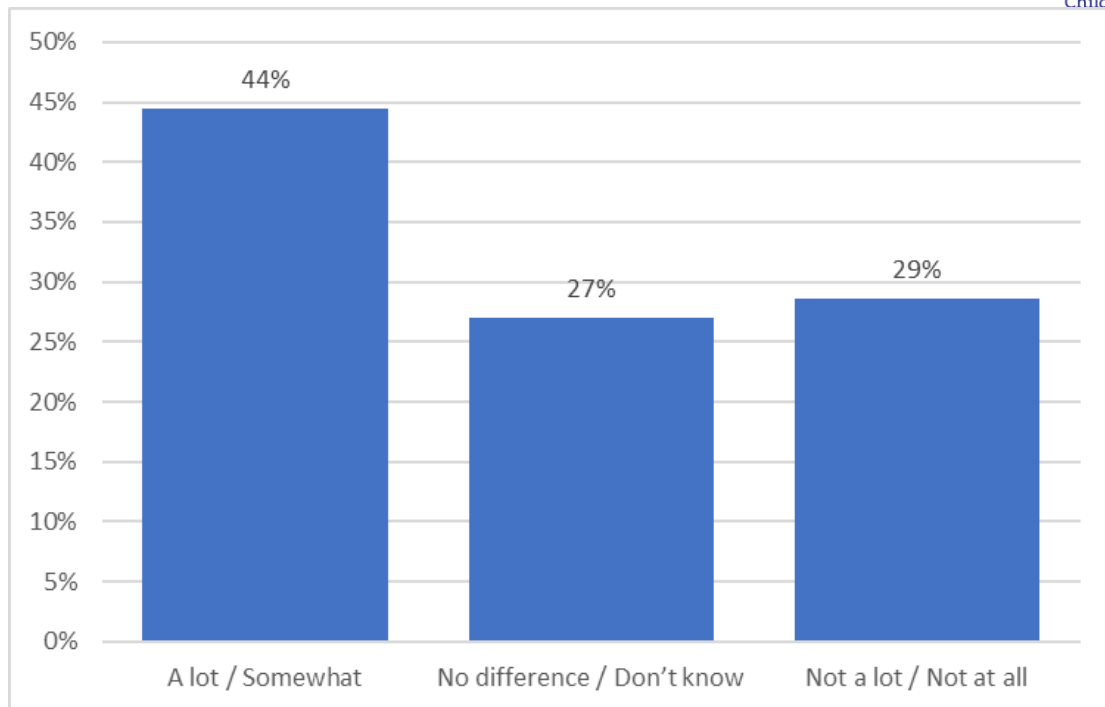
Parents said that it would be better for them, currently the only way they know about any services is talking to other parents. They felt that the current system is very disjointed and spend hours searching for activities and support. They said that they lose track of who they have spoken to and that even Social Workers do not understand the process. A single point of access would be easier for them and professionals to navigate. They asked about how this would work practically, who could refer and how it would affect the service that they receive. There were also concerns about a potential influx if it became apparent that there was an easier way to access the services. Parents said that it is such a battle to get any support and questioned whether it was deliberately hard.

Parents said we need to change the wording around inclusive because it is not - being inclusive is supporting any disability, any need which most services cannot do

Staff felt that it makes sense to have a joined-up assessment and review for all short breaks services. They felt that it would be interesting to see how it works in practice. They felt that the benefits would be that families would not need to repeat their story multiple times and reviews might be timelier. They felt that the support for the identified need may improve and gave examples of transitions such as turning 18, individual support such as buddies.

Staff felt that it would be good to have a single care plan across all services for a really joined up approach.

4. To what extent do you feel that improved access and flexibility of non-residential short breaks would reduce your need/or the need for residential short breaks?



The majority (44%) of people agreed that increasing the number of non-residential short breaks services would reduce need and reduce the need for residential short breaks. Parents on the waiting list and Other Practitioners were the groups that agreed the most. Staff agreed the least with a higher percentage not knowing or not thinking it would make a difference. (126 people answered the question).

Many families are saying that residential short breaks are so key because it gives them a good night's sleep and a proper break, which couldn't be replicated in the same way in non-residential short breaks or other services. Extended breaks are needed for many families to prevent burnout. A lot of families said that this may make a difference for other families but felt it was not the case for their family.

Focus Group response

Parents said that there is a gap between residential and non-residential services. They said that there are children who miss out as they do not fit the remit. It was noted that early help services used to be well funded during the 'Aiming High' funding days and that these services worked. They said that an overnight at JGS or Squirrels is the nearest thing that some children get to having a sleepover at a friend's house as this is something these children will never experience.

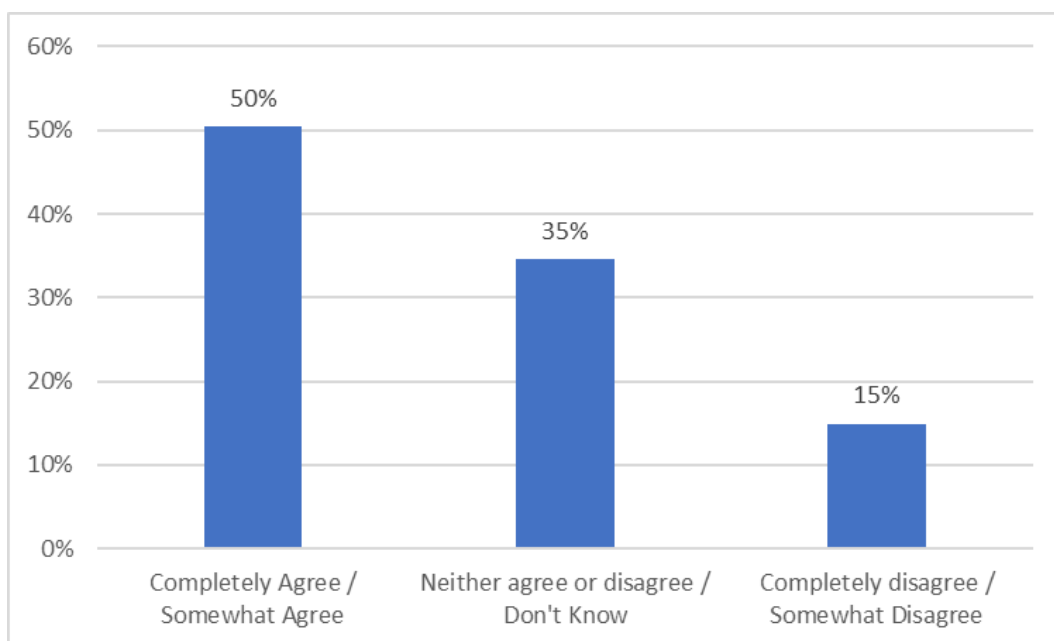
One parent said that they understand how much more overnights cost compared with non-residential services but that it might prevent crisis situations if there was more regular and frequent support. They said that for children who do not have very complex needs, overnights could be much cheaper and that her son has accessed overnights at the Lowther centre (Scout centre), and it makes a huge difference. Overnights do not have to be expensive.

Staff and parents were both quick to say that residential short breaks are still needed and are a lifeline to families. Staff did however agree that there needs to be earlier engagement with families and that we need to overcome the barriers that children needing 1:1 and 2:1 staffing currently face.

Staff were able to identify occasions when it might have been better to offer a non-residential short break. There was one case where a young person would have benefitted from a daybreak instead of an overnight break.

They said that sometimes parents need parenting classes to give parents confidence in using strategies and tools to support their child. Staff said that many children come in later (RSB) but should have come in earlier, if a young person comes in at 15 it is very hard to then manage their behaviour. This traumatic time might have been avoided if earlier support had been put in. They did say though that the threshold is too high to access services. Sometimes the issues leading to needing the support are not resolved and the parent's emotions and trauma should not be underestimated.

5. To what extent to you agree/ disagree that there needs to be an increase of non-residential short breaks opportunities to children requiring 1 or 2 members of staff, even if it means that the overall number of available places will be less frequent as a result



The majority of respondents completely agreed or somewhat agreed that there needed to be more non-residential short breaks for children requiring 1:1 or 2:1 staffing to attend services. All groups except staff had a majority agreeing with the statement. The majority of staff either did not know or neither agreed nor disagreed.

Many families agree with this statement as they say they were told their child could not access non-residential services due to the staffing levels needed. There are many comments that all children should be able to access these services, no matter their need. Some respondents commented that there should be more opportunities but not at the expense of spaces.

There was a comment that residential short breaks are the services most in demand, rather than non-residential short breaks therefore this does not make sense to increase these and reduce residential short breaks. For some children, routine is very important and infrequent support can be more disruptive than supportive.

Focus Group response

Both parents/carers and staff felt that there was a need for non-residential short breaks for children with 1:1 and 2:1 staffing needs. Both groups also had examples of children who could not attend non-residential short breaks for multiple reasons such as non residential could not support, not enough staff, cost of venues, increased challenges such as medical / behavioural, no service for children wearing pads, complexities of mixing with other children, parents having to attend or using their PA to attend.

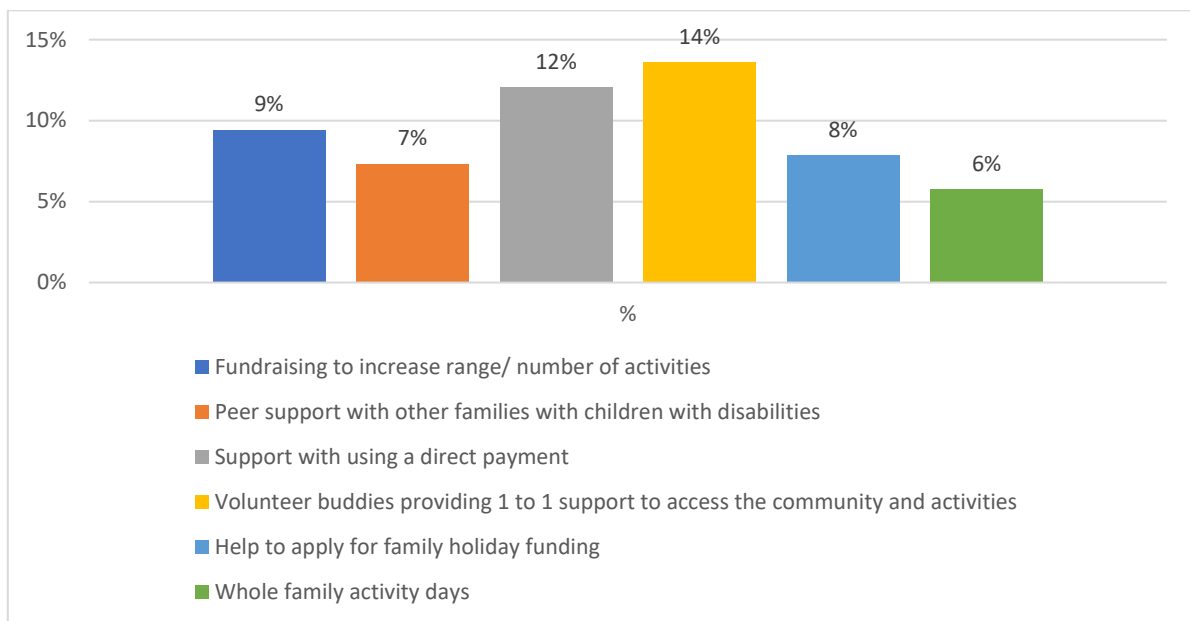
They felt the results of not being able to attend are a lack of opportunities to make friends, family breakdown, families desperately need respite, reduced services as children get older, parents do not get a break as have to attend and children don't get time away from parents.

Parents commented that there are a lot of services for children with low or moderate need but there is nothing for children with high needs.

6. Are the additional services below, suggested as part of the previous engagement sessions, still relevant?

Additional services

In the 2020 engagement, the below services were suggested to be included in future short breaks services. The survey asked which services were still relevant and would be beneficial.



Volunteer buddies providing 1 to 1 support to access the community had the highest response at 14%, followed by support with direct payments at 12%. These categories received 38-43% of their responses from parents of children who access short breaks. A fundraising Post had the highest preference from staff in the short breaks services. The service with the highest response from professionals was also for support with using direct payments.

In the survey, there was also opportunity for parents to add any other services their children with disabilities accessed, shown in the list below:

- Autism East Midlands
- Brookside Day Services

- Kingsley Special Academy
- The Cube Disability
- DISC – Disability Inclusive Sports Club
- NAB – Northamptonshire Association for the Blind
- Flipper Club
- The Green Patch
- Ups n Downs
- KTFC – Kettering Town Football Club - Multi-Disability football
- Northampton Saints Wheelchair Rugby
- Youth Inspired
- Spectrum Northants
- Disability Bowls England
- Born to Perform Dance School

There were lots of suggestions for holiday clubs to be run as part of schools, including more clubs and activities for teenagers. Some families have said it would be nice to have events for the whole family including siblings as it is positive to see other families in similar situations and to feel understood and supported by one another. Some said that it is important to tailor activities to the age and interest of children.

Comments on support to find funding for family holidays were to find features such as safe space beds and fenced in gardens. Some families said it would be beneficial if short breaks services could allow families to also go on holiday with other children in the family. Some parents also said they would benefit from support in the home with paperwork and forms.

93% attended activities specifically for people with disabilities.

54% of those attending residential short breaks received 1 night per month and 72% attending non-residential went 1 day per week.

Focus Group response

The most popular option at the focus groups was Buddies for both staff and parents with examples of children who would benefit from a service like this. Parents said that young people have personalised budgets but cannot find people in order to spend it. They also felt that it was a good opportunity to be with younger people.

A parent felt that the fundraising post is a good idea.

Staff felt that the support to get funding for holidays would be beneficial but also to help families with days out too. It was asked whether the holidays would be abroad. It was suggested that activities and holidays for children who need low noise would be good. It was noted that Northamptonshire Carers do holidays.

Parents felt that somebody to help parents find out what services are available would be beneficial, parents and carers lives are so busy that they often miss what is going on.

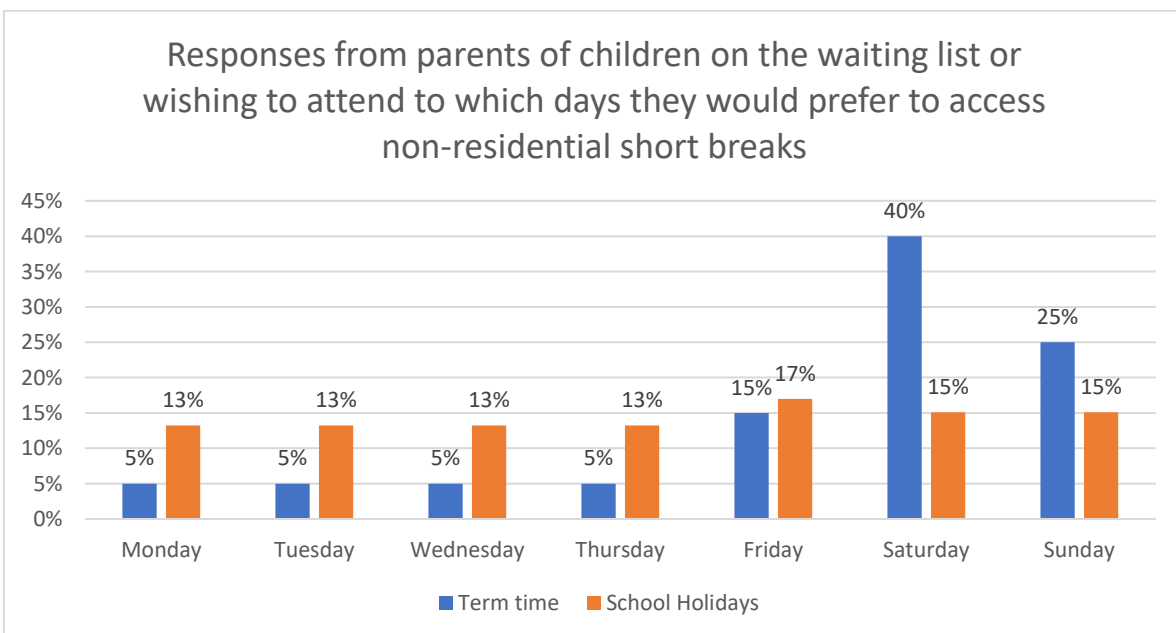
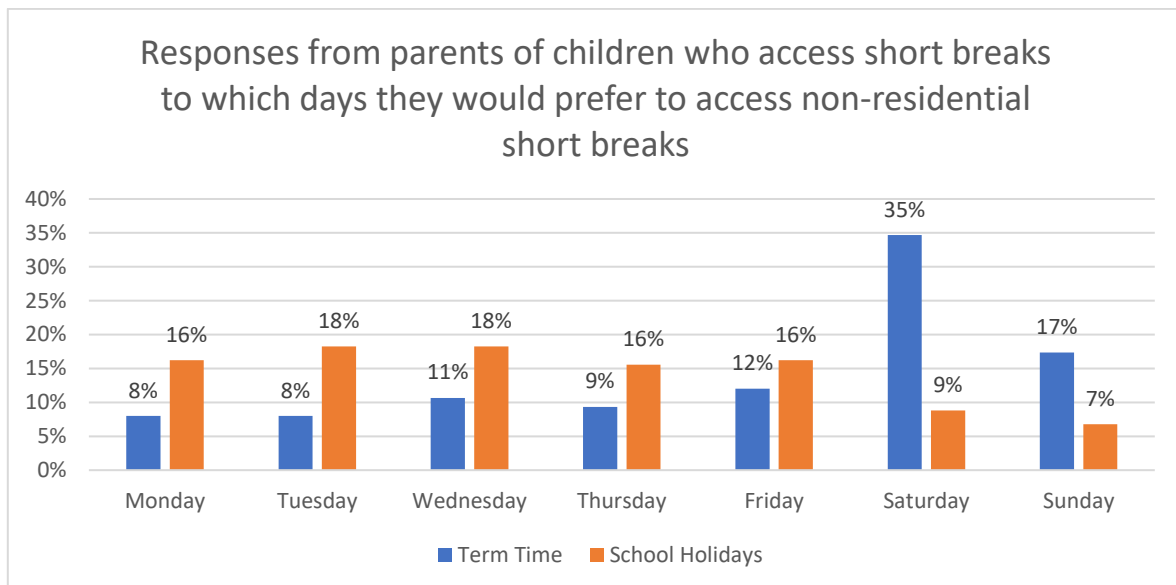
Parents commented that they do not want volunteers looking after their children.

Staff said that a gap is people to be PAs for families direct payments.

Parents suggested that services until young people were 25 would be good.

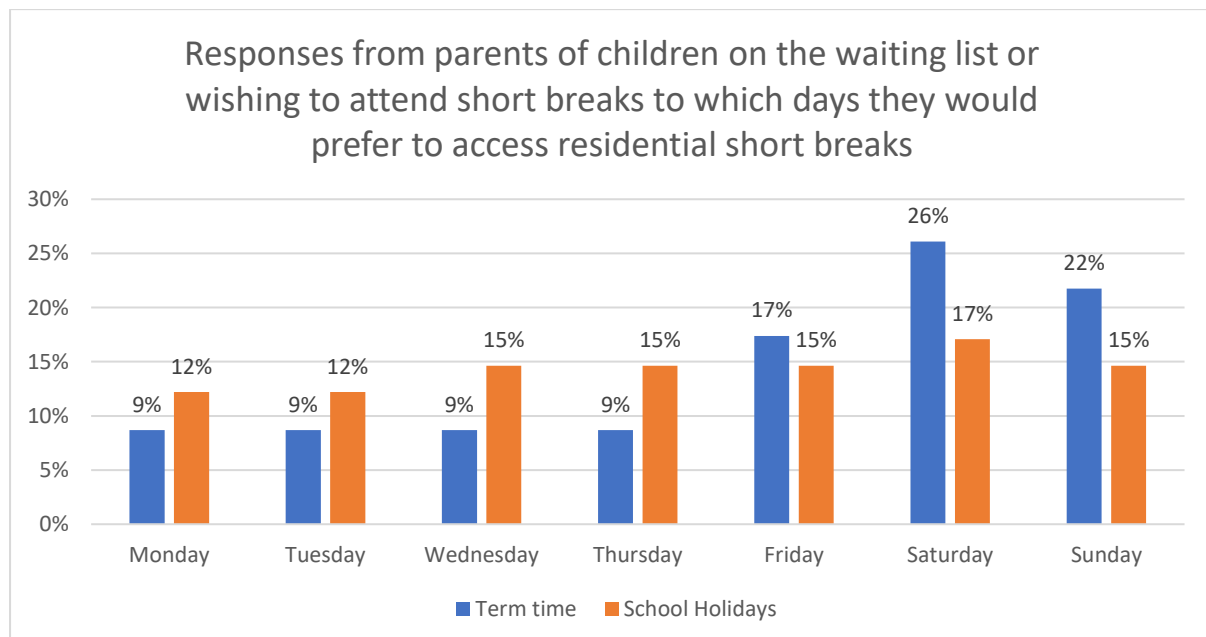
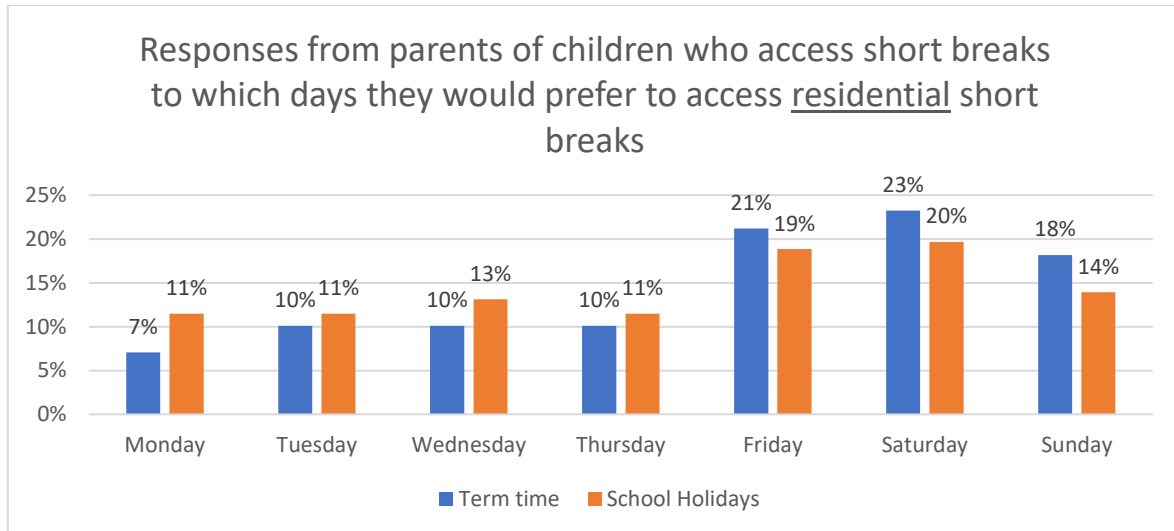
Parents / Carers were asked their preferred days to access short breaks services

Non residential short breaks - During term time, the preferred day for both groups of parents, accessing and on the waiting list, is Saturday (36% of all responses), followed by Sunday (19%) then Friday (13%). In school holidays, the preferred days for parents of children who are accessing short breaks are Tuesday and Wednesday (18%), followed by Friday and Monday (16%). For parents of children on the waiting list or wishing to attend short breaks, their preferred day in school holidays is Friday (17%), followed by Saturday and Sunday (15%).



Residential Short Breaks

Residential short breaks, the preferred day during term time for both groups of parents is Saturday (24% of all responses), followed by Friday (20%) and Sunday (19%). The least preferred day term time for both groups is Monday (7%). In school holidays, the preferred day is also Saturday for both groups (19%), again followed by Friday (18%) and Sunday (14%). The least preferred days in school holidays for residential short breaks are Monday and Tuesday (12%).



The survey allowed for parents to add additional comments about their preferred days. Parents say that school can help in the week and provide respite, but weekend respite is needed for parents to either spend time together with their other children or simply have a small break. Many parents saying that without short breaks they would be in crisis and their children would have to go into full time care.

Many commented that their children like routine and consistency, therefore, would be more suited to have the same day each week or month. Some parents said due to staffing needs their children

cannot access non-residential breaks. Parents want their children to have social interaction with others.

In the focus groups, parents did not specify a day but said that in term time they generally prefer weekends. Staff agreed that weekends tend to be the most popular days particularly Friday and Saturday.

Many parents were asking how to access non-residential and residential short breaks and what the criteria is as they have not heard about it previously.

Focus Groups

Any other comments

Both parents and staff said that good communication was very important to them and for commissioners to keep their promises. The unknown and uncertainty is unsettling for them.

Staff asked what the training would be like going forward and whether there would be training for transitions.

One parent said the local offer is not parent friendly, but another said that the Northants Local Offer is good.

Parents said that there are such long waiting lists for everything. Parents felt that you must get in crisis before you are offered any support.

There were comments about the EHCP process and that there are now too many children with an EHCP. One parent said that the LA changed her EHCP without being told.

Parents said that so many families are in crisis.

Other Services

Parents and practitioners shared details of other services that are available and will add these to the list of mapped services.