

# GETTING IT RIGHT IN WEST SUSSEX

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**A survey of family carer  
experiences of behaviour  
support and wellbeing**

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## Introduction

The Getting It Right project in West Sussex aimed to ensure that children and young people (0-25) with learning disabilities at risk of behaviours that challenge will receive the right support, in the right place and at the right time, from well informed professionals and staff so they can live a happier and more inclusive life in their community. A logic model was created with the West Sussex Steering Group to reflect these aims (see appendix 1). More information about the project is available [here](#)

A Family Carer Survey was completed with family carers in West Sussex as part of the Getting It Right project between February 2020 and June 2021. The survey questions are available in appendix 2.

This survey aimed to build on the views shared in two focus groups carried out with families in West Sussex at the beginning of the project and look at family carers views and experiences of:

- Behaviour Support Services – services aimed at improving understanding and supporting a child or young person with behaviours described as challenging
- Support for carers for their own wellbeing and resilience and that of their family
- The impact of Covid on both access to services, the needs of their relative and family, and their own wellbeing.

As well as understanding what is and is not working for families in West Sussex, we also sought to gather carers' recommendations for what they would like to see in the future both for their relatives and for themselves as carers.

The survey was developed in partnership with commissioners, professionals, and family carers from across the county and captured the views and experiences of 98 carers over 3 weeks in September 2020. The survey was circulated with the support of the Getting It Right Steering Group including West Sussex County Council, and Sussex NHS Partnership Trust. The survey was mainly distributed via West Sussex schools and colleges and carers organisations including West Sussex Parent Carers Forum and Carers Support West Sussex.

Our sincere thanks to all families who took part, the steering group members who helped shape the survey and those who helped distribute it to families, especially during a difficult year where so many were impacted by Covid-19 and its restrictions.

For details of how the information gathered was analysed see appendix 3.

## Executive summary

Families identified several positive factors, or enablers, which helped when accessing support for their relative's challenging behaviours including engaging with and feeling listened to by schools, colleges, nurseries and portage services. Receiving valuable support from practical support and services, such as SENDIASS, when preparing EHCP plans was also noted as a positive.

Regarding their own needs, families reported that Families Wellbeing Grants were of benefit as carers identified they represented a feeling of value, acknowledgement and flexibility. However, they were found to be too short-term, and others found it challenging to use the grant appropriately due to their relative's care needs. Support from the Parent Carers Forum and Carers Support West Sussex were also valued by those who accessed it.

Despite the positives, the survey identified far more barriers than enablers to accessing support. Barriers included delays, long waiting times and lack of access to support – particularly early intervention for younger children, and a dependence on families to seek out their own information and support services. Families also identified support not meeting their relative's health and wellbeing needs, lack of appropriate information and inexperienced or uninformed professionals.

A number of barriers were also identified which prevent families from accessing support for their own needs. These included lack of accessible respite services, lack of long-term planning for their relative and family, lack of early intervention support, and a lack of support for the family as a whole - especially sibling support.

Regarding the Covid-19 pandemic, families shared many different experiences around how their relative, their families, and they themselves had been impacted. These experiences included the development of new or increasing severity of challenging behaviour as well as a negative impact on the mental health of themselves and their families. It was also reported that their relative missed out on support during the pandemic. Increased employment and financial anxiety, and families needing to juggle a significantly larger number of responsibilities were also mentioned.

Some families did however experience some positives from the first national lockdown. Respondents mentioned the removal of stress that came along with engaging in activities such as travelling and getting ready for school, being able to spend more time together as a family, and finding it easier to access support online than it had previously been in person and receiving support from other family members who were also at home.

From the survey, a number of recommendations can be made to inform better support for this group of carers. The recommendations encompassed supporting the development and provision of information about challenging behaviours for parents and professionals and building on good engagement of families and partnership working in schools. Additionally, improving respite services, increasing support for young families, encouraging services to think long term about a young person's care and involve their families in this process and ensuring support is more accessible for families were recommended. This report also recommends carrying out further research to explore barriers for families from Black Asian and Minority Ethnic communities, or families with relatives in residential care.

## Survey Reach and Respondents

Firstly, we report the demographics of family carers who responded to the survey, the reach of the survey and the networks through which the survey was distributed.

### About the Family Carers who completed the survey

#### Carer age, relationship to relative and location

Most people completing the survey (96.6%) were parents of children or young people whose behaviours challenge. Outside of this group a small number of adoptive parents and a very small number of extended family members responded to the survey. Carers sharing their experiences were aged between 22 and 65 years of age and we were pleased to have reached respondents from across the county covering most postcode areas (for further details of the geographical spread of responses see appendix 4).

#### Ethnic background

Families were asked to describe their ethnic background. We were pleased to hear from carers who represented the diversity of the local population, however, the number of carers completing the survey from Black Asian and Minority Ethnic communities was very small making it difficult to understand if there are specific barriers to support impacting families from Black Asian and Minority Ethnic communities (Figure 1).

Description of Ethnic Background	Percentage of Survey Respondents (%)	Percentage of local population according to ONS Census Data 2011 (%) <sup>1</sup>
White/White British	93.9	94.8
Asian/ Asian British	1	3.5
Black/ African/ Caribbean/Black British	0	0.9
Mixed/ Multiple Ethnic Group	3	1.5
Other Ethnic Group	0	0.3
Rather not say	1	

Figure 1 Chart showing survey respondents by ethnic background

<sup>1</sup> Office of National Statistics (2011), UK Census, adapted for NOMIS local area profile. Available at <https://www.nomisweb.co.uk/reports/localarea?compare=E10000032>

## Additional Caring Responsibilities

Research tells us that carers of people with a learning disability have amongst the most intensive caring responsibilities of any group of carers in the UK<sup>2,3</sup> especially as many will have caring responsibilities in relation to other family members in addition to the child or young person they are completing the survey about.<sup>4</sup>

To get a full picture of families' caring responsibilities we asked respondents to let us know about other caring responsibilities they have, in addition to supporting their relative with learning disabilities and/or autism. Carers were able to select several options from a list of possible caring responsibilities.

Of carers who responded, 62.5% reported an additional caring responsibility, 36.6% reported two or more additional responsibilities and 10.2% reported three or more. Figure 2 below provides details of additional caring responsibilities.

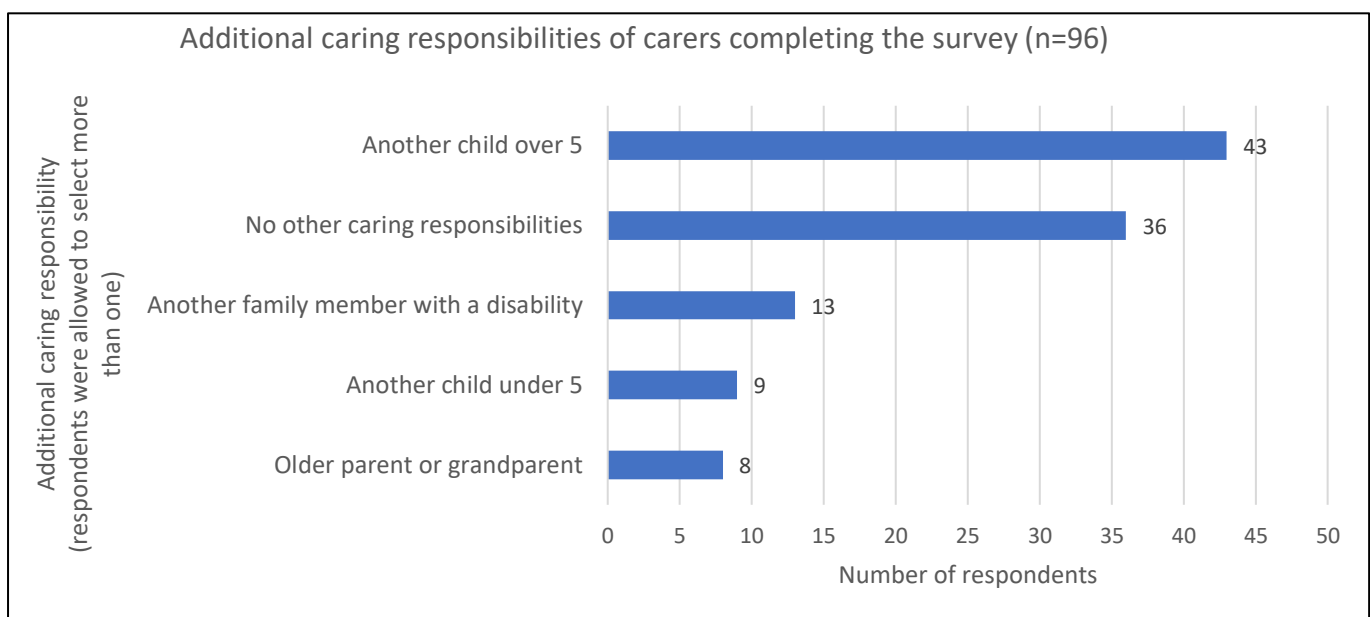


Figure 2 Chart showing additional caring responsibilities of respondents

### Key points

- The survey reached a wide range of carers from across West Sussex
- In this report we will aim to understand how support and services differ for families with additional caring responsibilities
- Further research in West Sussex may wish to focus on investigating access to services and support for:
  - People identifying themselves as being from Black Asian and Minority Ethnic communities
  - People living in areas of the county with low or no respondents (RH17 & BN44)
  - Carers from the extended family such as grandparents and siblings

<sup>2</sup>Carers UK. (2016). State of Caring 2016. Available at : <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016#:~:text=07%20May%202016%20Carers%20UK%20carries%20out%20an,Survey%20carried%20out%20by%20Carers%20UK%20to%20date>

<sup>3</sup> McGill, P, Papachristoforou, E, Cooper, V. (2006). Support for family carers of children and young people with developmental disabilities and challenging behaviour. Child: Care, Health & Development 32(2): 159–165.

<sup>4</sup> Office for National Statistics (2019) More than one in four sandwich carers report symptoms of mental ill-health.

Available at:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/articles/morethanoneinfoursandwichcarersreportsymptomsofmentallillhealth/2019-01-14>

## About The Children and Young People Represented in the Survey

In this section we provide an overview of the families, children and young people represented in the survey and discuss some of the ways we will use this information to help understand support and services in the wider report.

### Age and Gender

We gathered the views of families caring for children as young as 2 all the way up to young people aged 25. We know that families have differing needs and will need access to different services as their relatives grow. We also know that many families experience challenges as their relatives move from child to adult services and through different educational settings. Therefore, we will look at children and young people grouped into four age groups broadly aligned with educational stages: preschool aged (under 5 years old), primary school aged children (5-11 years old), secondary school aged children (12-18 years old) and college or school leavers (19 -25 years old). See figure 3 below.

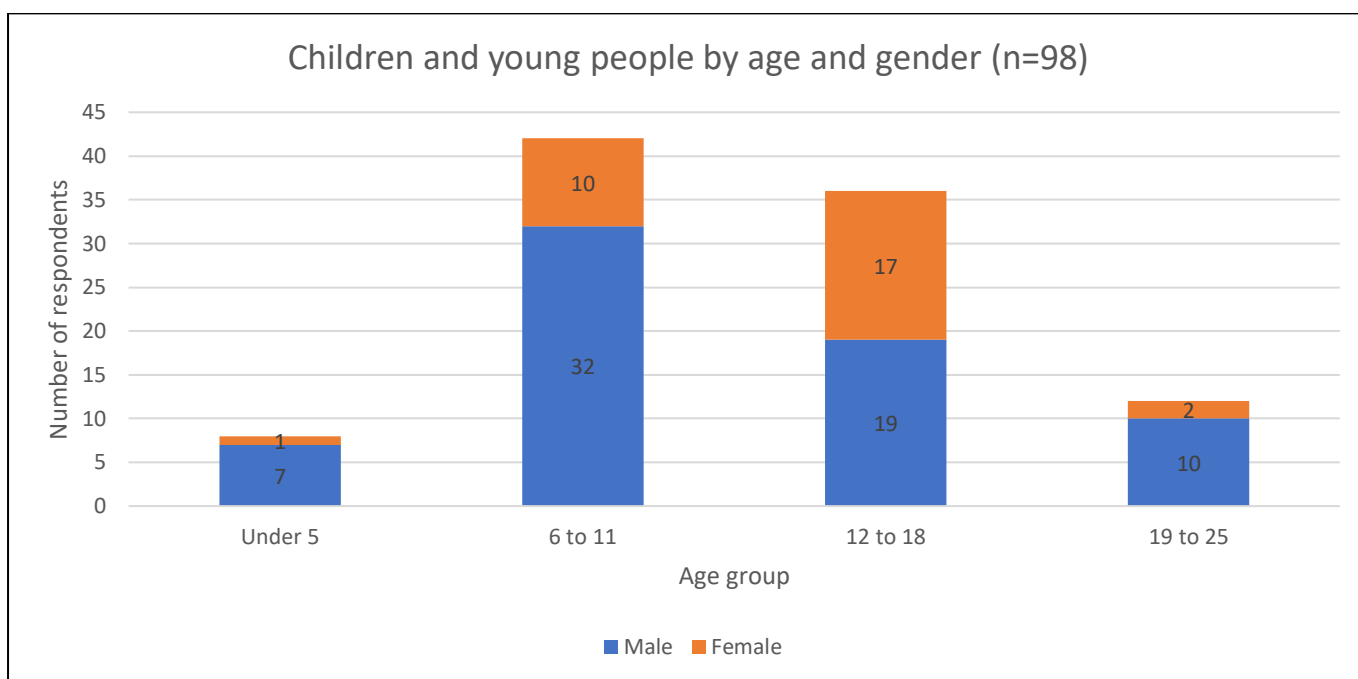


Figure 3 Chart showing children and young people represented in the survey by age group and gender

As the survey was distributed via local schools and colleges as well as carers organisations it is not surprising that most children and young people represented in the study are of school age.

### Nursery, school and college attendance

79% of respondent's relatives referred to in the study were regularly attending school, college or nursery prior to Covid restrictions (1.3% were awaiting a placement and 2.6% were being home-schooled). Most children and young people not in school were in the 18-25 age group where young people are old enough to leave full time education. Only 6% of respondent's relatives not in school or college were aged 6 to 18 years. The majority of children and young people lived at home full time (94.9%). Others attended residential schools part of the time or lived in supported accommodation.



## Describing Learning Disability, Autism and other conditions and diagnoses

A range of diagnoses were described by family carers. Autism was the most common diagnosis. This was frequently selected alongside diagnosed learning disability. 70.7% of respondents had a relative with 2 or more diagnoses/ conditions. In addition to the options given to respondents, families also described Post Traumatic Stress Disorder, anxiety, depression, sensory issues and ADHD. In this report we aim to look at the experience of all families as a whole, but also recognise the different needs and experiences of children and young people with different diagnoses or conditions and their families. Due to the challenges around waiting times for diagnostic assessments, carers of children with suspected autism or suspected learning disability have been included in the same groups as those with diagnosed autism or learning disability. The information on diagnosis is displayed in figure 4 below.

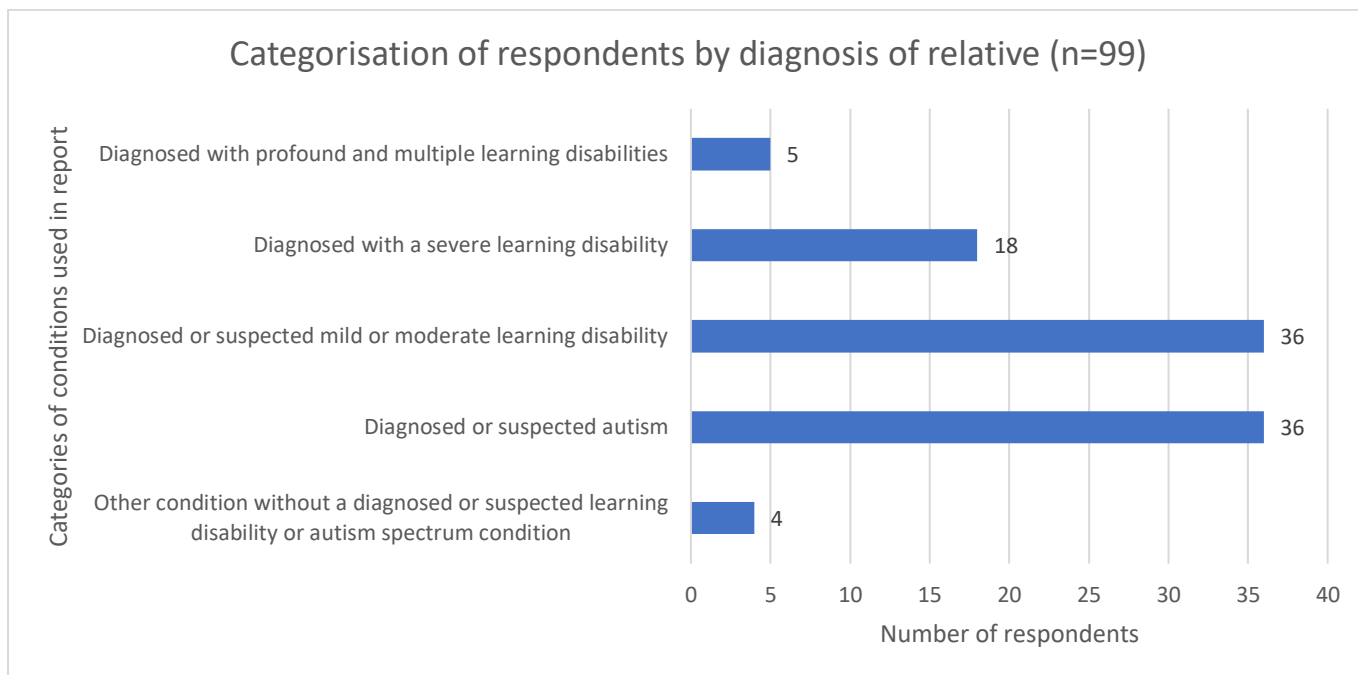


Figure 4 Chart showing categorisation of respondents by condition/diagnosis of relative

Family carers were asked to comment on their experiences of diagnosis. This question was added to the survey following feedback from the two focus groups. Overall, families reported significant waiting times for diagnosis with 69.8% of all respondents reporting waiting over a year to receive a diagnosis for their relative. Many families mentioned wait times of 5 years or more, reported feeling their concerns being ignored by professionals and described having to pay for private assessments to achieve a diagnostic assessment of their child's special educational needs.

Carers of girls and young women were more likely to report longer wait times with 86.2% reporting waiting a year or more in comparison to 62.7% of families caring for boys and young men. There is some evidence that children with a learning disability tended to be diagnosed slightly earlier than those with autism and a learning disability.

### Key points

- Children and young people were mostly of school aged and lived at home
- The most common diagnosis of the children and young people was autism
- Long waiting times were reported to access diagnostic assessments

# Family Carer Experiences of Challenging Behaviours and Accessing Behaviour Support

## Experience of Challenging Behaviour

### Development of Challenging Behaviours and their frequency

89.9% of families responding to the survey reported that their relative displayed challenging behaviours. Of these, families on average reported first noticing challenging behaviours from their relative aged between 3.5 and 4 years old and the majority (68.5%) reported that their relative is likely to display challenging behaviours every day.

Typically, families caring for an individual with autism or suspected autism (with no reported learning disability) reported more frequent incidences of challenging behaviours, with 96.4% of respondents reporting incidences more than once a week. This compares to 88.9% of carers of individuals with a severe learning disability, 75.9% with a diagnosed or suspected learning disability, and 75% with a profound or multiple learning disability.

### The impact of Challenging Behaviours on a child or young person

We asked families to share with us how their relative's challenging behaviour impacted on their lives, the life of their relative, and their relative's access to services like their GP, community spaces and activities like parks and libraries, on a scale from 1 (very negative) to 5 (no impact).

Families reported a negative impact on their relative's emotional and physical health due to challenging behaviours with 71.7% reporting that their relative was experiencing physical and emotional difficulties which are hard to manage or actual physical and/or emotional harm due to their behaviours. There is some indication that carers of individuals with a severe learning disability were more likely to report very negative impacts on their relative's physical and emotional health, with 23.8% reporting the most severe impact compared to just 7.7% of other respondents.

*"The aggressive and controlling behaviours take over and he gets very distressed. Once started these behaviours are near impossible to stop."*

*Comment from Family about their child's behaviour*

Only 23.9% of families reported experiencing negative or very negative impact on their relative's access to services (meaning that services were very difficult or impossible to access). There is some indication that families caring for a child or young person with a severe learning disability were more likely to report more negative impact than other groups, with 31.8% reporting negative or very negative impact in comparison to 16.7% of other carers.

*"We have learnt ways to better manage difficult situations - and also know the trigger signs to exit if its is too difficult to manage. I tend to go into activities with positivity but mostly behaviour means we have to exit activities."*

*"I have to pre-prepare people before appointments as to how they can support it going well. After school clubs and holiday clubs are not an option as he needs 1:1 support"*

*Comments from families on Accessing Services with their Child*

## Key Points

- Typically, families started to notice challenging behaviours developing when their relative was 3 and a half to 4 years old. The majority of children and young people displayed challenging behaviour daily.
- Overall, families were more likely to report significant impact on their relative's physical and emotional health than reduced access to services due to behaviour
- Of the families responding to the survey, families caring for a child or young person with severe learning disabilities were more likely to report a very negative impact on their relative's physical and emotional health due to challenging behaviour, and most likely to report that their relative's behaviour had a negative impact on access to services and activities.

## Accessing Information and Support for Challenging Behaviours

In the survey, families were asked if and how they asked for support with their relative's behaviour and how they felt schools and services support their relative's behaviour. Families were also asked what information and support they accessed and what tools they used to support their relative.

### Asking for support directly through services

83.2% of respondents had asked for help with their relative's behaviour. Most commonly families approached school or college, their GP, or local Childhood and Adolescent Mental Health Services (CAMHS). Other services families mentioned included the Social Care team, Child Development Centre, Aspens and MASH, speech and language therapists, epilepsy nurses, and psychiatrists. The families caring for an adopted child mentioned the post adoption social care support as being a key source of support.

Families reported asking between 1 and 9 services, and on average approached 4 services for support. 42.4% of carers had approached 5 or more services. For further details see appendix 5.

Respondents were asked to tell us if they had received support when requested. Overall, requests for support were generally met with some positive responses with 81.7% reporting that they received some level of support. However, a significantly lower number of carers of children and young people with a profound or multiple learning disabilities reported positive outcomes, with only a third reporting receiving any form of support.

Carers of children and young people with no reported autism or learning disability gave the most positive responses with 100% of families reporting receiving support. Families caring for individuals with autism and no learning disability reported the second highest levels of positive outcomes, at 94.7%. 80% of families caring for children and young people with a learning disability and severe learning disability reported receiving some level of support.

There was a significant difference in carers reporting positive responses to requests for support with 76.7% of carers of children and young people with a learning disability reporting receiving support or some support and 86.9% of carers of children and young people with autism and no learning disability (n=66).

Families across all groups experienced delays to accessing support with the majority of families waiting over a year (56.9%). Once support was received, families had mixed experiences of its quality with 31% of families across all groups being happy or very happy with the support they received and 35% being unhappy or very unhappy.

Many families shared with us their frustrations of having their concerns dismissed or actions not being taken after repeatedly raising concerns, many also shared experiences of being turned away from services.

*"We approached CAMHS for support with PICA and we had one appointment in which services were offered but never materialised. We received a short break when our child was younger, and we received direct payments now they are older, and we have been happy with these services"*

*"We are getting help since lockdown but otherwise it's just written down. No help offered on how to improve the situation"*

*"We've been waiting three years for help at CDC, been discharged three times from CAMHS. Discharged from early help! Had MASH referrals when my son has tried to hurt himself and still nothing"*

*"School didn't witness any challenging behaviour, so we weren't believed. Social services finally referred him for behaviour support plan and sensory support but didn't provide any other support in terms of direct payments to enable us to have some respite"*

*Comments from Families about Accessing Behaviour Support*

Several families were pleased with the support they received particularly from schools, nursery, and portage but many also had concerns about continuity between services and situations changing as their relative got older. That said, families caring for older relatives were more likely to report being happy or very happy with

their support (33.3% aged 12-18, 25% aged 18+) than those caring for younger children (9.3% aged 6-11, 0% 5 and under).

Families also spoke about the onus on them to seek out information and support around behaviour and feeling that through their own research and experience as a parent they often knew more about behaviour and supporting a child or young person with complex needs than the professionals they approached.

*“We got lots of great info from the SENCO at my daughters’ Primary school, who pointed us in lots of directions about services that can help with eating disorders and sleep problems and all sorts. Very happy with the help we were given there. My child has now just moved to secondary education so waiting to see if the service is as good, but so far very happy with communication from school SENCO staff”*

*“I received fantastic emotional support from Portage. My child’s mainstream nursery were certainly supportive but I had more experience and knowledge (being child’s parent) about challenging behaviour than the staff (who hadn’t had a child with complex needs before). I really hoped my child’s SEN school teachers would give me knowledge and practical ideas around the challenging behaviour that presents itself – I have been surprised and disappointed that they just have not. There have been times where I’ve actively sought their advice about how to work with / improve some challenging behaviours and they have literally said ‘we don’t know’.”*

*Comments from Families about Accessing Behaviour Support*

### Schools and their role in Behaviour Support

The majority of families whose relative normally attends a nursery, school or college felt that their nursery/ school/ college were doing quite a good or a very good job of managing their relative’s behaviour (72.9%) and the majority felt that staff listened to them and worked with them to manage their relative’s behaviour quite well or very well (68.3%). However, respondents also noted that often their relative’s behaviour was not seen or exhibited in the same ways or to the same extent in the school environment, for some families this leads to concerns that some behaviours not being noted could result in their relative’s needs not being fully recognised in a school or college setting.

*“I would say my child’s challenges at school are probably not being heard or seen enough, her challenging behaviour is within the home or outside of the home in my care. At school I worry she cannot communicate her needs and therefore misses out on learning”*

Several carers had experienced their relative moving from mainstream to SEN provision and most welcomed the additional support and understanding. For some families, consistency in approach was a concern, as was understanding of behaviour and complex needs as one family shared with us in this example.

*“My son rocks when distressed, disengaged or a lesson is going too slow. He rarely rocks at home, and when he does he can help us identify why and he will then stop rocking. This isn’t the case at school where the deferent rocking is not seen as a communication that he wants to change something about the situation he is in.”*

### Accessing support and services through SENDIAS and the Local Offer

Families were asked to tell us if they had heard of the Local Offer and Special Educational Needs and Disability Information Advice and Support service (SENDIAS) if they had used them and how useful they found them.

The majority of families (74.7%) had heard of the Local Offer, although carers of children aged 6-11 (78.1%) and 12-18 (88.9%) had significantly higher levels of awareness than those caring for relatives over 18 (60%). Those caring for children under 5 reported much lower levels of awareness (16.7%).

Of those who had heard of the Local Offer, 52.7% had used it. There were mixed reviews of its usefulness, however, with carers as likely to report the offer being “extremely” or “very useful” as they were to report the Local Offer as “not so useful” or “not useful at all”. There is some indication that carers of children and young

people with different diagnoses and conditions experience the usefulness of the network in different ways. Carers of children and young people with profound and/ or multiple learning disabilities or a mild or moderate learning disability were likely to rate the service as more useful, and carers of a child or young person with Asperger Syndrome, autism, or other conditions not considered a learning disability were more likely to report the service as being less useful.

When asked to comment on the Local Offer, families reported that whilst the service was useful for seeing other families' reviews and comments, often the information was hard to find, linked to services no longer available or lacking in information relevant to their needs.

*"There has been barely any up-to-date information. When I was desperate for childcare, I was told to use the local offer and there was literally none available. Many website links and groups don't exist any longer"*

*"It is useful to read parents comments and reviews"*

*"The website is not easy to navigate Emails directing me to services on the Local Offer are easier"*

*Comments from Families on the Local Offer*

The majority (68.1%) of families reported having heard of SENDAISS and 58% of those families reporting having used the service. There was a significant difference in families caring for children and young people of different ages accessing the service, with carers of children aged 6-11 years old being most likely to report having used the service (76.0%), in comparison with lower levels among carers with children aged 12-18 (47.1%) and over 18 (33.3%). No families caring for children under 5 reporting use of the service. Families who had used the service were overall positive about the service with 63.4% of carers reporting the service as being "extremely or very useful" compared to just 6.7% of carers reporting the service being not so useful. Families leaving comments about the service gave good feedback on support given to them around the EHCP process and other guidance. Some families wished for more practical support.

*"They gave me advice with our transition from statement to EHCP. Explained a lot about the process that the council did not."*

*"Useful in terms of guidance. I wish they could do the whole choosing and communicating with new schools with me as it's so daunting"*

*Comments from families on their use of the SENDAISS Service*

### Family experiences of using specialist approaches and communication tools to support their relative

To understand what families were already putting in place to support their relative we asked them about tools and strategies they used to support their relative's communication and behaviours. Respondents were able to select from a list of suggested tools and approaches and were able to select as many as applied to their situation. Most families were trying to implement a regular routine to support their relative, whilst fewer reported using a formalised behaviour support plan or specialist communication tools (Figure 5). When asked what other tools and strategies they used many families spoke about methods they had found to help their relative communicate, using technology like an iPad or visual aids, therapeutic parenting, allowing time for their relative to calm down in a quiet space, using social stories and other ways of preparing their relative for events or activities and being aware of what might trigger behaviour and making necessary adjustments. Some families also mentioned having been prescribed medication to manage anxiety and sleep problems.

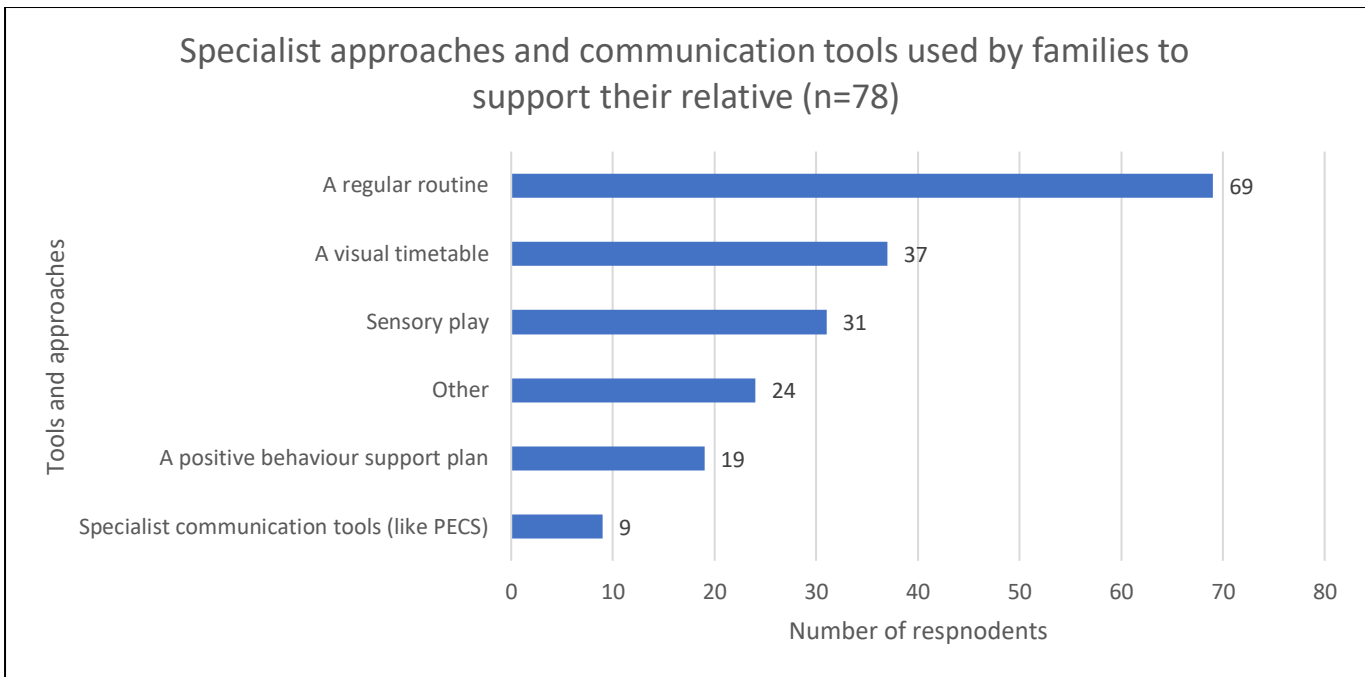


Figure 5 Chart showing use of specialist approaches and communication tools

When asked why they didn't use these tools the majority of families told us it was because they had never been offered or told about them (Figure 6).

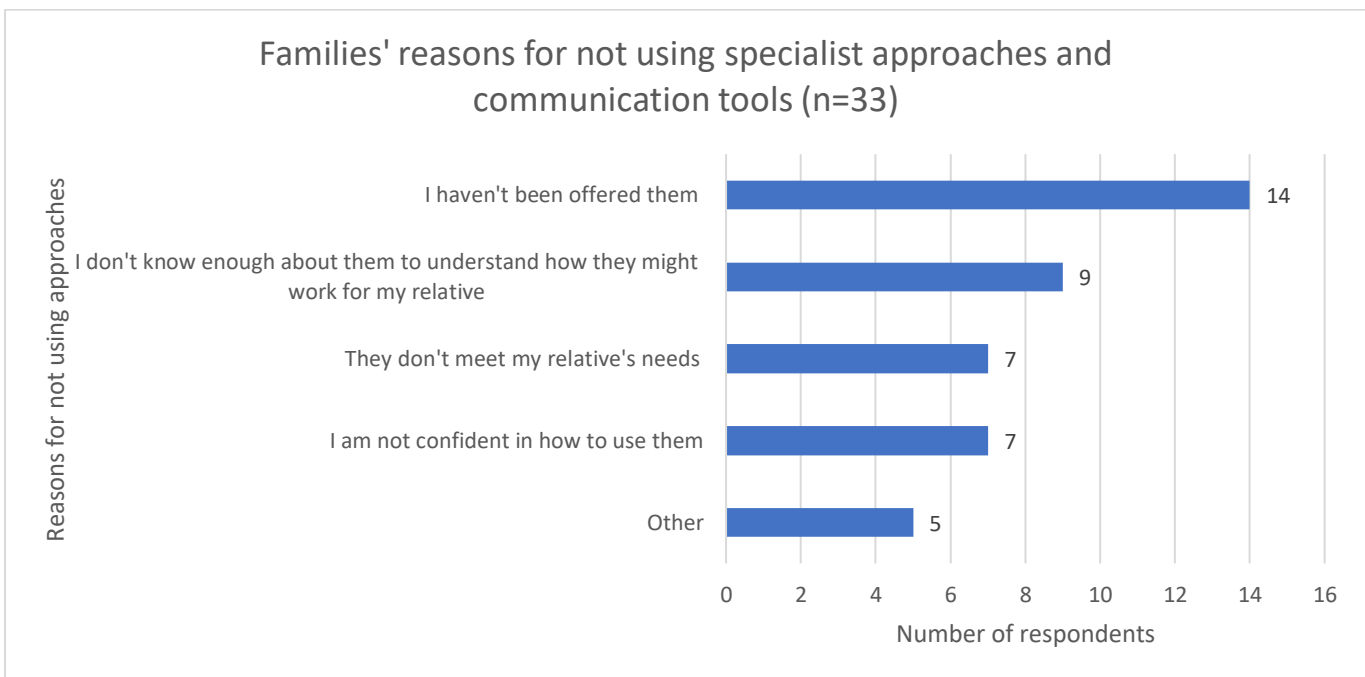


Figure 6 Chart showing families' reasons for not using specialist approaches and tools

Other reasons why families told us they did not use specialist tools or strategies included having developed their own strategies which worked with their relative, or because they felt their relative was unresponsive to the tools and strategies. Again, this emphasised the experience of carers as proactively researching and developing their own strategies.

*“We have researched ways to support her ourselves as we haven't had much input on that front. She's mostly distressed at night, which stops her sleeping. So, we need to gently distract her whilst making sure she feels heard. She often doesn't sleep for days at a time but because her anxiety is what's causing this, we are being pushed from one professional to another who think it's someone else's responsibility to help! We are currently waiting on a referral to Maudsley Hospital because it's clear the support my daughter needs isn't available in West Sussex”*

Accessing information about supporting a child or young person with additional needs and challenging behaviours

We asked families how easy it was to find information on supporting their relative and accessing services, and how they felt about the quality of the information they were accessing. Information on supporting a child or young person with autism was considered both more accessible and better quality than information on supporting a relative with a learning disability or who displays challenging behaviours (Figure 7). Finding information on financial support was not as sought after but proportionally seen as easier to find and of good quality. Most significantly, sourcing good quality information on supporting a relative with challenging behaviours was considered most difficult to source and of lower quality (Figure 8).

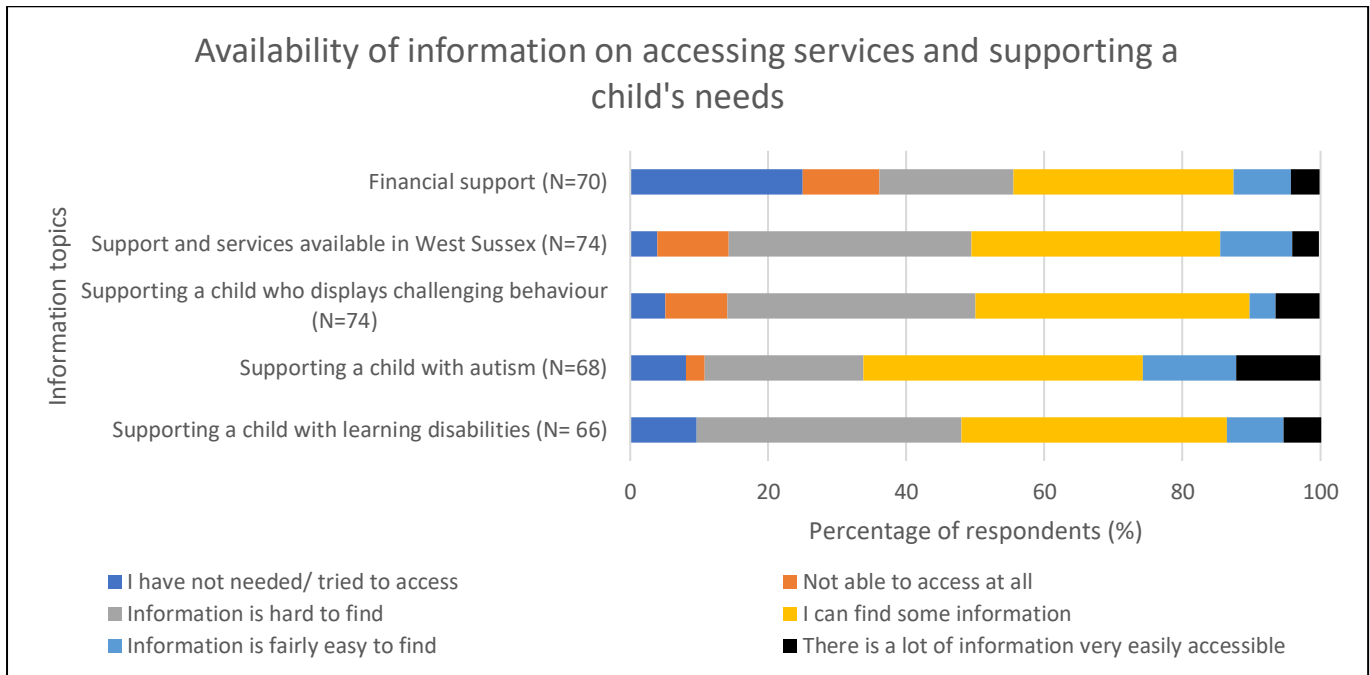


Figure 7 Chart showing availability of information on accessing services and supporting a child's needs

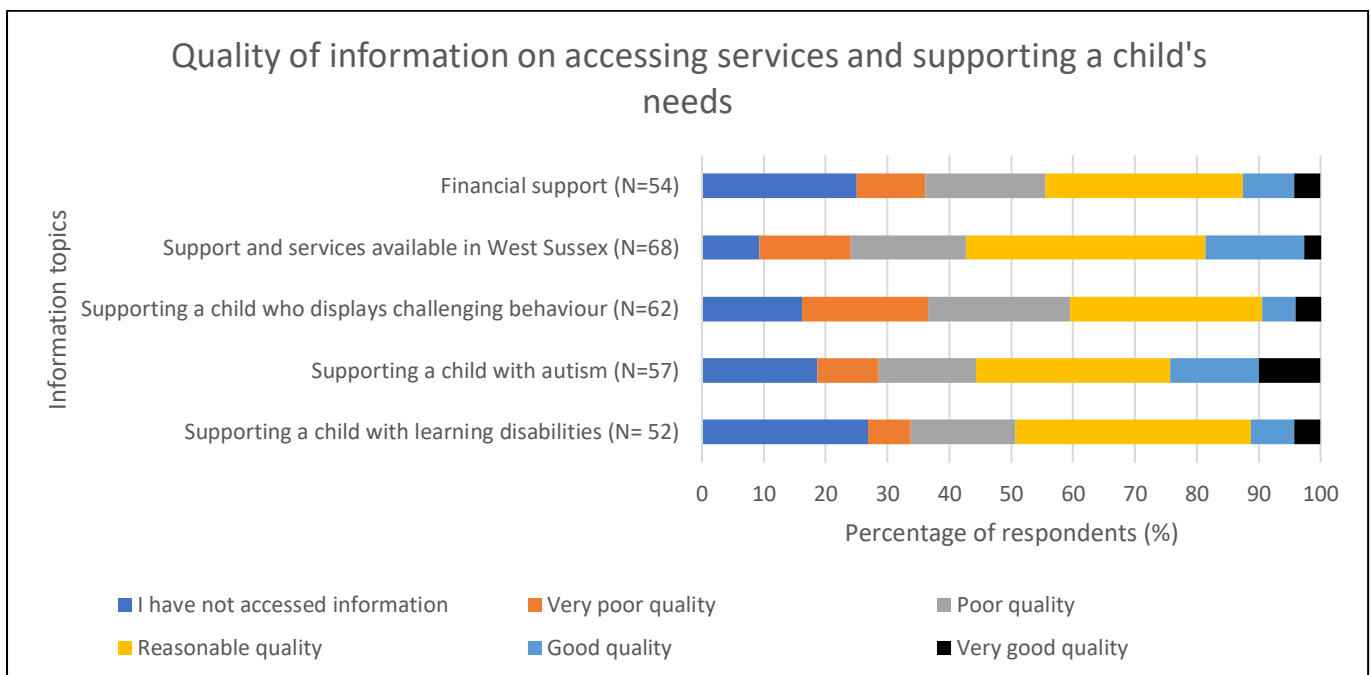


Figure 8 Chart showing quality of information on accessing services and supporting a child's needs



In their comments, families shared with us frustrations over having to search out information in many places which are often hard to navigate, and not knowing what they can trust as accurate information.

*“Information about support, services and activities for severely disabled children in West Sussex is rapidly deteriorating. We say a bright and happy future for my son under every child matters, but there is so little available now for someone permanently in a wheelchair. His world shrinks every year”*

*“There is just so much information on Autism it is difficult to know what to believe and what not to”*

*“No information is readily given I have only found out things through other parent carers or support charities. However, services are so overrun that when we do find something is usually full or there are long waiting times”*

*“Information is hard to find, the local offer system is complex and often information is hidden in areas “for professionals” etc when it should appear in the “parents” section too. The best information and support is provided by charities, like Reaching Families, FSW, WSPCF, Aspens etc”*

*Families’ comments on the frustration associated with a lack of appropriate support information*

## Key Points

- Families were most likely to approach their relative's school or college, a GP or CAMHS services for support with challenging behaviours
- Family carers of children and young people with a learning disability reported less positive outcomes asking for support with challenging behaviours than those caring for children and young people with autism. Carers of children and young people with profound and multiple learning disabilities were particularly more likely to report partial or low levels of support for challenging behaviour.
- All carers reported significant waiting times for services to support them, as well as reporting frequently being turned away from, or passed between services where children and young people with a learning disability or challenging behaviours are not seen to be part of a service's remit.
- Carers of younger children reported less positive responses from services to requests for support with challenging behaviours.
- The majority of carers with relatives in school were pleased with the level of support they received and the way the school worked with them as carers, although, there are concerns about consistency of approach between school and home.
- Both SENDIAS and the Local Offer had high levels of awareness among carers but were significantly less well known and used by carers of children under 5.
- The Local Offer had mixed reviews from families with reports of out of date and irrelevant information. Carers of children and young people with PMLD or a mild or moderate learning disability were slightly more likely to report the service as being more useful than other groups.
- SENDIAS was seen by some carers as specifically helpful for information on developing an EHCP – again, it was less likely to be accessed by carers of children under 5.
- Most families did not use tools like behaviour support plans or communication tools to support their relative. Of the families who told us why they didn't use these tools the majority said they hadn't been offered or told about them. Instead, families were developing their own tools and approaches through experimentation and knowledge of their relative.
- Information for families on supporting their relative was patchy. Families reported a lot of information about caring for a child or young person with autism, but families were overwhelmed with information and found identifying good quality information difficult. Families reported lower levels of availability and satisfaction with information on supporting a child or young person with a learning disability.
- Information about supporting a child or young person displaying challenging behaviours was seen as less available and of lower quality.

# Family Carer Wellbeing and Resilience

## Understanding Wellbeing and Resilience

Carer wellbeing and resilience was a key topic which came up in the initial focus group meetings. When we discussed the topic of resilience with families, we came up with the following definition which we used to inform the survey:

***‘The capacity to recover quickly from difficulties. Resilience does not mean putting up with bad practice, but rather it is strengthening the ability to manage unexpected challenges that arise.’***

To understand wellbeing and resilience the survey looked at:

- Carer’s life satisfaction
- Carer’s feelings of confidence in supporting their relative
- How carers experienced the impact of challenging behaviours on their own and their family’s physical and emotional health
- Feeling positive about the future
- Feeling listened to in developing plans for the future and services
- Accessing Support and Information around needs and rights as a carer

## Life Satisfaction

Life satisfaction is an indicator used across charity and government projects to assess general wellbeing as recommended by the Centre for Wellbeing.<sup>5</sup> Families were asked to rate how satisfied they felt with their lives on a scale from 0 to 10, with 0 being ‘not at all satisfied’ and 10 being ‘completely satisfied’. Only 2.8% of families responded reporting life satisfaction ratings of 9 or above. This puts them well below the normal national average of 30% but also significantly lower than national figures during the first lockdown which saw only 6.1% of the population report these higher levels.<sup>6</sup> Comparing life satisfaction across carers with additional caring responsibilities and carers of children and young people with different level of learning disability, autism and connected conditions showed no significant difference between groups.

## Carer Confidence

Carers were asked to rate their confidence in caring for their relative from 1 (not at all confident) to 5 (extremely confident), 82.4% reported feeling at least somewhat confident in supporting their relative. When we looked at the responses of carers with additional caring responsibilities there was some evidence that carers with two or more additional caring responsibilities were less likely to report these higher levels of confidence, with only 60% reporting feeling somewhat confident or more.

Comments from families revealed carers’ concerns about the long-term care of their relative and the pressures of providing the right support for them as well as the intensive caring requirements and the impact on their own wellbeing.

*“I feel I know him very well, but I haven’t been able to change or really improve his behaviours much. I am daunted, depressed and horrified at thought of looking after him at home as he gets further into Adulthood. I think he needs to be living in a supervised place of residence where he is able to come home sometimes. I think he needs more than just me. I also think he is better with access to open spaces and countryside”.*

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<sup>5</sup> What Works Wellbeing Homepage. Available at: <https://whatworkswellbeing.org>

<sup>6</sup> Office for National Statistics. (2021). Measures of National Well-being Dashboard. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuresofnationalwellbeingdashboard/2018-04-25>

*“Being confident to provide the right care personally and wanting to therefore giving up your own life/independence/ability to work/pay in to a pension etc are 2 entirely different things – it gets harder as they get older because their lack of potential independence gets more obvious and the gap between them and their peers shows more – as does your own position in life – you have been so focused on caring that there is nothing left for you personally. What might be the right care for them is probably detrimental to you.”*

*“My son is 20 – my biggest worry is services / housing for him when we cannot advocate or care for him”*

*Comments from Families about their Role and Confidence as a Carer*

### The impact of challenging behaviour on carers and their families

When asked about the impact of challenging behaviours on the family, 67.4% of carers reported either negative or very negative impact on the physical and emotional health of family members due to their relative’s challenging behaviours. This did not change significantly between groups of carers. Families shared some difficult stories about the challenges they face. Several were particularly concerned about siblings and the impact on their wellbeing.

*“Taking him out and about is always a trial and you feel full of stress and anxiety the whole time looking out for triggers that may set him off. You feel like you have no peace or life of your own.”*

*“The house is permanently like walking on eggshells”*

*“Mostly affected are my other children and managing the care of a child with a disability in a separated home environment.”*

As well as sharing the challenges, some families also shared steps they had taken to reduce the impact or support the family to cope better with the stresses of challenging behaviours.

*“Older sibling suffers with anxiety due to these behaviours and has had play therapy to help him deal with this.”*

*“Historically very negative impact, but we have been looking at the reason why he self-harms and has challenging behaviour. We have seen improvement over the last year and he is improving still.”*

*Comments from families on the impact of behaviour on them and their family*

### Planning for the future and managing challenges

We asked families to share their hopes for the future for their relative and family. More than half of respondents were able to tell us something positive about what they wanted for their relative and their families. These ranged from short term hopes for more stable placements, better outcomes in specific areas of support they felt their relative was lacking, to more general hopes about future happiness. Most commonly families mentioned their relative being able to achieve their potential in education and living as independently as possible, and being able to form connections and make friends and have their needs and choices heard and recognised.

*“To be happy and well supported. To be in a shared family placement when we can no longer care for him (not a care home) To have an advocate who fully understands his needs”*

*“That she becomes more independent, She learns ways to deal with her emotions & anxiety.”*

*“Trying to navigate adult services. Hope to find activities suitable for him to do”*

*Comments from families on their hopes for their relative’s future*

Whilst many respondents felt able to share positive plans and hopes for the future, 49.2% felt they were not or not often listened to by professionals in planning for the future and 20.3% felt they were not supported at all by professionals to make future plans a reality. Some families felt they had not been offered opportunities to discuss their relative's future at all with professionals or that their input as carers was not considered. There was a sense that services were focused on what they could do now and not in the future. When families did feel that they had been listened to and understood, often services were too busy or not available to help even if they felt their concerns were listened to and understood.

*"I think College want to focus on what they feel they are doing for my son and not his future when he leaves."*

*"The GP does not seem to listen to my input and my relative has communication difficulties and therefore cannot explain the difficulties – catch 22"*

*"Listened to and understood mostly. But there just aren't the services available to help"*

*"They can listen but the services are not there & it's down to the family"*

*Comments from families on support to plan their relative's future*

### Key Points

- Family Carers across the survey reported much lower levels of life satisfaction than the general population.
- Generally, families were fairly confident in their caring responsibilities, but carers with multiple caring responsibilities had significantly lower levels of confidence.
- Most carers surveyed reported negative or very negative impact of challenging behaviours on their own and their families emotional and physical wellbeing.
- Whilst families were mostly able to express positive thoughts about the future of their relative, many did not feel supported by services and professionals to help make these plans a reality. Some services felt too focused on short term goals.

## Accessing Information and Support for Carers

### Access to Carers Assessments and support from services

Families were asked if they had received a Parent Carers Needs Assessment or Carers Assessment, and how well supported they and their family feel generally by services in West Sussex. They were also asked about their knowledge and use of the West Sussex Parent Carers Forum, Carers Support West Sussex, and the Parent Carers Wellbeing Grant.

Only 14.7% of carers reported having a Parent Carers Needs Assessment (16.2% were not sure if they had or not). Carers of children and young people with a severe learning disability were more likely to have had an assessment than other groups. This is demonstrated by the results which indicated 50% of carers with a relative with a severe learning disability reported having had an assessment, compared to 25% of carers with relatives without a learning disability or autism, and 4.8% of carers supporting a relative with autism or a mild or moderate learning disability. No carers of relatives with profound and multiple learning disabilities or Asperger Syndrome reported having received an assessment.

When families were asked how well they feel supported by carers groups and services, most families told us they felt less well supported than they hoped or not well supported at all (54.3%). Only 14.3% reported feeling well supported or very well supported.

There was a significant difference in ratings between carers with and without additional caring responsibilities, with all responses from carers with at least one other caring responsibility reporting feeling better supported. Several families told us in the comments that they did not access any services for their family wellbeing, and whilst there were some families sharing good experiences with some services, there were concerns that several support services were no longer running.

*“Fantastic Young Carers group that my other child attends. There was a parent-led group that my husband and I went to together but sadly it finished as too much for the parents to run.”*

*“My older sons used to attend a sibling’s group at Autism Sussex. This no longer exists.”*

*Comments from families on support for their family and their caring role*

### Access to support via Carers Networks

69.3% of families had heard of Carers Support West Sussex. Awareness was significantly higher in carers of older children. No carers of the under 5s, 70% of carers of children aged 6-11, 75.4% of carers of young people ages 12-18, and 90% of carers of young people aged over 18 reported awareness of the service. 55.8% of those who had heard of the network had used its services, and the majority (93.1%) rated it as at least somewhat useful. Families shared some good feedback regarding fast responses to specific queries, others said some of the content was not so relevant for them and some questioned why they weren't signposted to the service earlier i.e., why they weren't connected when registering for carers allowance for example.

80.3% of families knew about the West Sussex Parent Carers Forum. Similar to the responses regarding Carers Support West Sussex, there was a larger awareness among carers with older children. 90% of carers of a young person aged over 18 were aware of the forum, 89.3% of those with a child aged 12-18 and 81.3% of those caring for children aged 6-11, whilst only 16.7% of those caring for a child under 5 had heard of the forum. 75% of those who had heard of the forum were members and most of them found the forum useful, with 86% rating the forum as at least somewhat useful. This was particularly true for carers of school-aged children (6-18) who were more likely to report the forum as being extremely useful than carers of other age groups. The forum also had good ratings from carers with additional caring responsibilities (carers with two or more additional caring responsibilities) 57% of whom rated the forum as extremely useful. The forum was praised by parents as a source of support and information about some services, several had not engaged with content from the forum regularly or recently and the lack of content for young adults was raised by one family.

45.9% of families had heard of the Health and Wellbeing Grant from West Sussex Parent Carers Forum and of those families 34.8% had received a grant. Carers reported using the grants for a range of uses from

exercise classes to acupuncture sessions or time spent with other family members and time away to relax. Families praised the grants for recognising their role and work as a carer, providing time to do something for themselves and relax. Some carers also mentioned that finding time to do something with the grant was challenging and whilst the grants were very helpful and appreciated the fact they were for a limited time meant that they couldn't carry on doing the same activities longer term.

*“It enabled me to do something for me, my needs are low on the list but with this funding I prioritised some self care”.*

*“I got to treat myself to a trip to London with my non autistic daughter.”*

*“The grant was helpful, but unfortunately I could not continue as I was unable to self-fund further sessions.”*

*“Receiving the grant is amazing and I feel provides both recognition and real support for me - as I have chosen to spend it on a service that I use at regular intervals throughout the year (hairdresser) it is 'the gift that keeps on giving' - it is there just for me and I get to relax”*

*Comments from families on use of the Health and Wellbeing Grant*

### Accessing information to support carers in their role

The availability of information for carers were noticeably less accessible than information on supporting a child or young person. Information on keeping in touch with other families was the least likely to be accessed but also rated as the most accessible and of better quality (Figure 9). Information on carers' rights and the rights of their relative was seen to be less accessible and least likely to be of good quality (Figure 10).

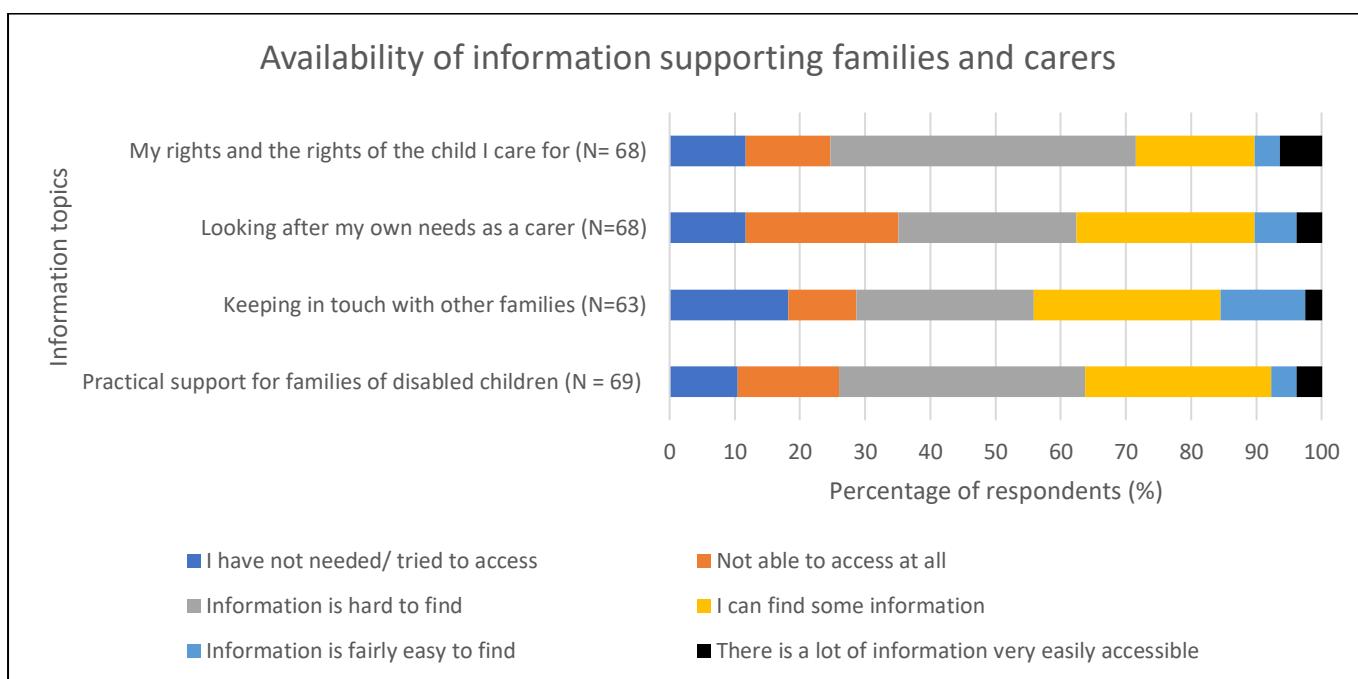


Figure 9 Chart showing availability of information supporting families and carers needs

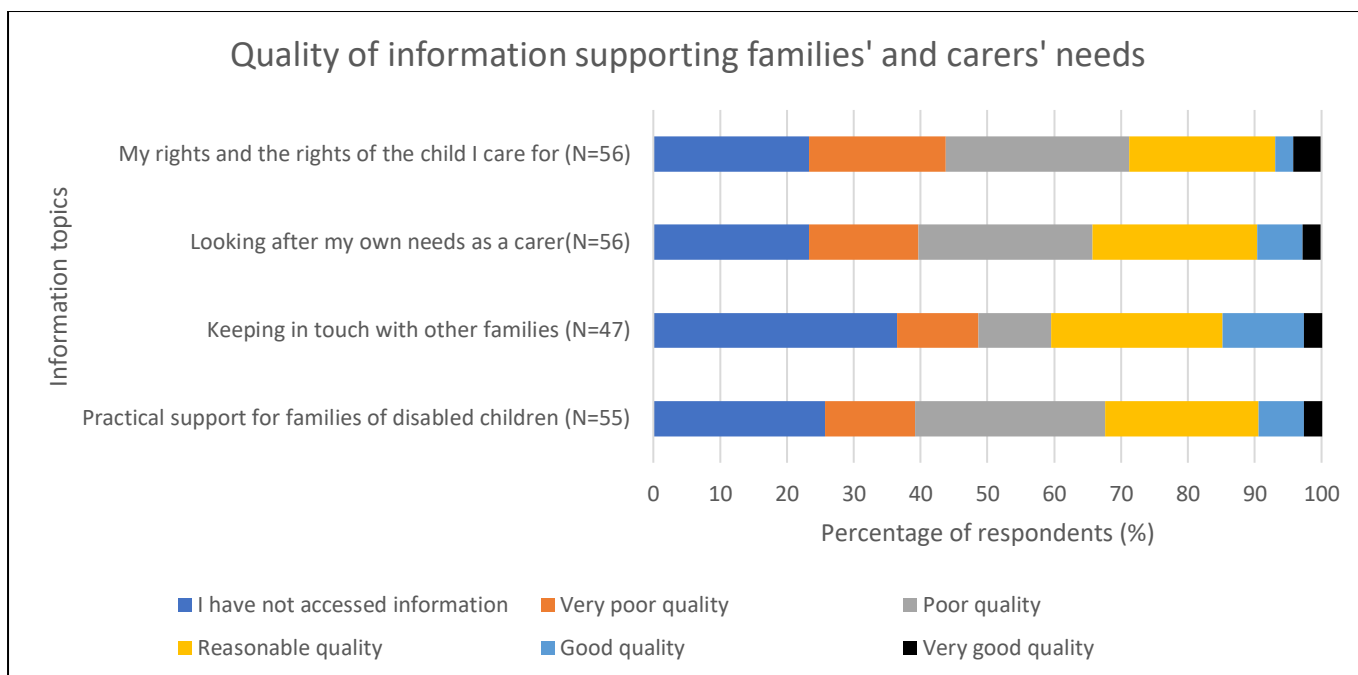


Figure 10 Chart to show quality of information on supporting families' and carers' needs

#### Key Points

- Generally, very few carers had received an assessment of their needs. Carers of individuals with a severe learning disability were more likely to have received either a parent carer needs assessment or carers assessment than those caring for children and young people with other diagnosis or condition, but this was still only half of carers completing the the survey.
- Overall, families did not feel well supported by services in the community. Major barriers were services failing due to lack of funding or capacity. Carers with additional caring responsibilities reported more positive experiences, this may indicate some services being better targeted at different groups of carers.
- Both West Sussex Parent Carers Forum and Carers Support West Sussex were widely known about. Both seemed to have a lower number of carers of younger children (under 5s) being aware or using their services and finding their services useful.
- Carers with additional caring responsibilities found the West Sussex Parent Carers Forum more useful than other groups. This may be due to finding support for their other caring responsibilities.
- Just over a third of carers completing the survey had received a health and wellbeing grant from West Sussex Parent Carers Forum. The grant was used for a wide range of purposes by carers who valued it not only for the support it offered for their health and wellbeing but also for the recognition it gave for their caring role.
- Access to information to support carers is patchy. Information related to carer and child rights was seen as the most difficult to source and of lower quality.



## The Impact of Covid

As the survey was carried out during lockdown restrictions due to Covid, it felt important to assess the impact of the restrictions on families to understand what was working normally and what might have changed due to the pandemic.

### The impact of Covid on the severity, frequency, and impact of Challenging Behaviours

Most families reported an increase in challenging behaviours during Covid restrictions (69.4%) with 45.8% of families reported that behaviours occur much more than usual. Carers also reported increased severity of behaviour (68.1% reporting an increase) and just under half (47.2%) reported the development of new challenging behaviours. There were no significant differences in either frequency, severity or new behaviours reported by carers of children and young people with different conditions and diagnoses or age group.

When asked to comment on these changes carers mostly referred to the disruption of routines, lack of school and connection with friends and family members as well as not being able to understand the changes, and masks and restrictions causing anxiety.

*“Lack of school routine for a sustained period of time and lack of social interaction set our daughter back, increased her anxiety and need for complete and total control of the household and her activities. Lack of freedom to see the friends that she has at last managed to make caused and continue to cause her great upset”*

*“Not being able to cuddle or get close to people and masks are scary for him”*

*“She can’t access anything she enjoys anymore and doesn’t understand why as her communication is so poor”*

*“She was unable to socialise with others at groups and has anxiety over going out now as she was shielding. It will be very difficult to get her to reintegrate when clubs reopen”*

*Comments from families on the challenges of Covid and their impact on challenging behaviours*

Some carers however did see some improvements to behaviour and positives for their relative. This was due mostly to reduced stress having to go to school, getting more one to one support and not having to engage in stressful or disliked activities. Greater time at home with family or with additional support to be able to understand behaviours and focus on trying new strategies and learning new skills was also mentioned.

*“No pressure to go to school/clubs etc so this has eased her anxiety slightly”*

*“He has been at home every day which makes him feel secure”*

*“During Covid school was better, less children, more interaction with teachers and a key worker assigned”*

*“We worked on independence and physical skills, and he has massively progressed in both. He took part in zoom before and in person sessions after the lockdown eased.”*

*Comments from families on the positive aspects of Covid and their impact on challenging behaviours*

### The Impact of Covid on Family Relationships and Wellbeing

Families mentioned both positive and negative aspects of being confined by the Covid restrictions on their family life. Many mentioned the considerable increased pressure on caring and the impact of this on their own and their family’s wellbeing.

*“Stress on whole family. Dealing with anger and demands made by child”*

*“Both my children were home-schooling with very different needs and of course needing activities and proper attention.”*

*“We’ve been housebound for much of it due to my son not wanting to leave the house. None of us have had a break from the behaviours. We’re all tired and drained from the experience and relationships have been tested.”*

Whilst others felt that the time together had strengthened bonds and given families time to learn about each other and undertake more activities together.

*“It’s been nice just being a family and altogether, but it’s been extremely tiring”*

*“The bond with his older brother strengthened and he became more physically confident as we did lots of climbing trees etc”*

For some, the financial impact of the pandemic was significant, and they found it difficult to access support as they were not automatically considered as a priority group for emergency support.

*“We had no help whatsoever, no access to priority and had to request help from a charity.”*

*“I’m absolutely, completely exhausted. My partner has lost his job – furloughed but ending soon with nothing. We pass the baton of childcare as I have gone to full-time work but feeling very stretched. Financial worry is high, we are not sure whether we will be able to keep our house once furloughing & mortgage holiday finishes next month.”*

### The impact of Covid on carers wellbeing

Overwhelmingly families told us of the increased caring demands on them and the negative impact of this on their wellbeing having to manage multiple responsibilities with less outside help.

*“I’ve not been able to have any of my own time”*

*“Juggling work and care needs has been difficult”*

*“Not seeing family and friends has been hard I’ve lost that support network”*

Although some found relief in not having to face some daily challenges with their relative

*“Not having the challenge of getting her up and out the door to school everyday has been a positive”*

For some, the pandemic offered more support for their caring role being able to access virtual support and online workshops whilst at home. However, this was not possible for all as some families felt the pressures of childcare too great to be able to devote time to finding support, they needed and missed the opportunity to attend in person meetings.

*“Lack of access to support groups. Have been unable to join any virtual groups as children at home prevent this”*

*“I was able to access online workshops from home due to not having to be at work.”*

With other members of the family were at home, some carers found support for their role and division of household tasks whilst many others missed the support from others outside their household.

*“My husband has worked from home. He was also on hand at times to supervise our son whilst I got groceries on my own”*

*“I am a key worker so there is the anxiety about going back to work. Lack of social interaction for me and before family bubbles were allowed, not being able to get family support.”*

## Key Points

- The restrictions, school closures and routine changes due to Covid-19 have resulted in increased frequency and severity of challenging behaviours.
- Carers found their own and their relative's levels of anxiety increased and struggled with explaining the restrictions to their relatives.
- Whilst many families have experienced significant increase in stress and caring responsibilities, many have also found positives in spending more time together and being more flexible to their relative's needs in regard to reducing anxiety around attending school and disliked activities.
- Not being automatically prioritised for support left some families in significant financial difficulties and having to seek support.
- Some families found accessing online and virtual support easier and found having other family members home increased support.
- Other families found the lack of face-to-face meetings, intense caring responsibilities, and inability to see extended family reduced their ability to access support.

## What Do Families Want?

Throughout the survey we asked carers to let us know what they felt was needed to support their relative, their own and their families' caring roles, and what information they felt was missing and would help them and their relative.

### Services and support for their relative

Many families wanted clearer information on services they could access for their relative. In particular, families wanted to be able to access more appropriate activities, support and leisure activities which take account of their relative's abilities and disabilities and services that are joined up so families are not referred to services which then cannot support them.

*"I'd like to be able to take my son along to a group that is aimed at his age-group"*

*"More activities for children with mental health/hidden disabilities in this area not so we have to travel 30/40 miles away with distressed child"*

*"Access to CAMHS & CDC instead of being declined constantly despite GP saying support is needed."*

Families also raised the issue of continuity of information and support from child to adult services. Supporting young people not to "fall off a cliff" in terms of support at 19.

*"(what is needed is) More availability, more relevant, more specific (services) to each client, more young adult services"*

*"(We need) Better support for adults. Services disappeared when he turned 18"*

### Services and Support for their own wellbeing and that of their families

The biggest request echoed in many responses across the survey was a need for respite services that are accessible, understand their relative's needs, and are provided for periods of time that enable families to have proper time to recharge and get other work/ tasks done. Several families mentioned having the support of a PA for their relative which had helped them to access support when needed.

*"Information is great but we really need more physical hands on help. Acknowledging that we are exhausted, trying to hold down jobs and a short break activity 1 hr away for an hour is just no where near enough"*

A large number of carers also wanted the support of someone to talk to who understands their situation and who they can go to for support. Many families commented on the need for sustainable support groups and activities for all the family. Carers were concerned that support groups and activities were often wound down due to lack of funding or volunteers meaning less availability for all groups. Alongside their own needs, families were also particularly concerned about support for siblings.

*"More funding, more volunteers, more online Zoom advice and support"*

*"These support services need proper funding so they can expand their help not continuous cutting by the council. 10 years ago there was amazing support in West Sussex for families with disabled children. Now there is a fraction left due to no financial support. There is no Theraplay, reduced Portage, Early bird training, Camelia Botnar centre, respite services like crossroads in Climping. Our family received all of this and it made a life changing difference."*

Many families wanted easier to access practical support and better signposting and referral that takes some of the onus off family carers to research, approach and put in place support for their relative whilst ensuring they still have an input and are respected for their knowledge of their relative's needs.

*“More understanding of how living with a child like this is, running a house, earning an income, and trying to deal with appointments, forms, benefits and planning for the future is an exhausting and stressful for parents and Carers. Chasing up on support constantly and reading reams of information to find what help you can access then to apply and get knocked back is soul destroying so eventually you don’t bother.”*

*“Being able to refer you to health professionals/behaviour support teams one point of contact for your 'issues' then support you to identify best solutions/signpost”*

### Information gaps and needs

Families told us that the most popular ways to receive information was online via websites, on email or face to face from professionals. When asked to suggest other ways of sharing information families suggested online workshops and support face to face via zoom. See appendix 6 for more information.

When discussing gaps in information families identified clear and accurate guidance on EHCP plan development and better information for young adults and transitioning to adult services.

Families also asked for more joined up working and clearer routes of referral with less reliance on families to chase and search out information and support.

*“Each service gives you information about different services, it is quite confusing. It would be better if they could give you information for all services and support instead of contacting each for different”*

*“There is so much information that it can be hard to unpick what can be helpful in the particular situation”*

## Conclusion & Recommendations

This survey aimed to improve understanding of the experiences of family carers of children and young people with a learning disability and/or who are autistic in West Sussex. Specifically, the survey investigated the barriers to/enablers of accessing both behaviour support for their relative and support for their own wellbeing and resilience. It also sought to find out the impact of Covid-19 on these experiences.

Families identified a number of positive factors, or enablers, which helped when accessing support for their relative's challenging behaviours:

- Schools, colleges, nurseries and portage services were highlighted as engaging and listening to families, with the majority of carers feeling that their relative's behaviour was well supported in these services. Even in some instances where families doubted that staff had specific knowledge or experience around challenging behaviours, they reported that they felt listened to, well supported emotionally, and engaged in their relative's care.
- Practical Support and Services were recognised and appreciated by families, with SENDIAS in particular reported as valued for their support in preparing EHCP plans.

Regarding their own needs, families reported that Family Wellbeing Grants and support from the Parent Carers forum and Carers Support West Sussex were of benefit.

- The Families Wellbeing Grants allowed for a flexible way for families to look after their own needs, spend time with other family members, and relax. The grants represented a feeling of value and acknowledgement for those who received them – but many found this support to be too short-term, and others found it challenging to use the grant exactly as they'd wish to due to their relative's care needs.
- Support from the Parent Carers Forum and Carers Support West Sussex was generally valued by those who had accessed it, with families reporting fast replies to specific concerns and good practical information.

The survey identified far more barriers to accessing this support, however. Families identified a number of barriers to accessing support for their relative's behaviour:

- Delays, lack of services and waiting times were reported as a significant barrier to receiving support from communities – with most families reporting a wait of a year or longer to receive support. Many reported that services in the community were operating waiting lists, or had reduced or stopped delivery of services due to lack of funding or available volunteers. Delays, lack of services and waiting times were reported as a significant barrier to receiving support from communities – with most families reporting a wait of a year or longer to receive support. Many reported that services in the community were operating waiting lists, or had reduced or stopped delivery of services due to lack of funding or available volunteers.
- Some services are not meeting the needs of children and young people or listening to families' concerns. Families caring for children and young people with a learning disability, particularly those with profound and multiple learning disabilities, found it less easy than other families to access community services. The barriers they reported included being turned away from a service because their relative did not meet the service's remit, and families' concerns not being taken seriously by professionals.
- All families reported that their relative's behaviour had a greater impact on their relative's wellbeing than on their access to services, but families of children and young people with severe learning disabilities reported significant impacts on both (wellbeing and access) – suggesting that there may be particular issues impacting children and young people with the most significant needs.
- Families reported a lack of information on supporting a child or young person with challenging behaviours. Reported use of specific behaviour focus strategies and communication tools was low,

and the majority of families reported that they had not been introduced to how to use such tools or strategies. Information on supporting a child or young person with challenging behaviour was reported as the least available and of lowest quality.

- Information was also reported as being out-of-date or inappropriate, with information often being provided for services which had long waiting lists, or which were inappropriate for their relative's needs. There were high levels of awareness of SENDIAS services and the Local Offer but mixed reviews of their usefulness, with the Local Offer reported as particularly hard to navigate. High quantity and but low quality of information was reported as a particular challenge for families of autistic children and young people.
- Families with younger children (under 5y/o) reported the lowest level of usage for Local Offer and SENDIAS, and lowest satisfaction with bursary and portage services. The lack of support for younger children was raised as an issue specifically regarding early intervention, with greater information needed for managing challenging behaviours, diagnosis, and access to services – particularly early intervention services.
- Professionals supporting children and young people with challenging behaviours were reported as lacking understanding, experience, and knowledge around these behaviours. Despite having sought and gained much information and understanding themselves, families reported that their input was not valued by professionals – even in instances where professionals themselves lacked experience and knowledge around supporting this group of children and young people.
- Dependence on families to source support and information was reported, with several comments stating that the onus is often on families to seek out services and information, rather than this support being offered through a joined-up referral process. On average families approached 4 services for support with their relative's behaviour, and families often developed their own tools and strategies for supporting their relative.

A number of barriers were also identified which prevent families from accessing support for their own needs:

- A lack of available, accessible and flexible respite services was reported, with families facing long travel times, short respite periods, and services unable to support their relatives when trying to access respite services. Respite was the most common answer when families were asked what additional support they needed.
- Lack of long-term planning for their relative and family, with the lack of certainty around the long-term support that their relative might be offered being reported by family carers as a barrier to feeling fully positive or confident in their role. Carers felt that services were focussed on immediate concerns and not long-term planning, and didn't feel listened to or supported when attempting to enact positive plans for their relative's future.
- Families reported a lack of Early Intervention and Support. Carers of children under 5 in particular were less connected to support from West Sussex Parent Carers Forum and Carers, and comments from families connected often highlighted frustrations that they had not accessed the service sooner.
- Finally, families also reported a lack of support for the family as a whole. Very few reported satisfaction with community support for their families and for supporting carers' roles. Of particular concern was the lack of support for siblings. Families reported that support that was previously available to them was no longer running.

Regarding the Covid-19 pandemic, families shared many different experiences around how their relative, their families, and they themselves had been impacted.

- Many families reported the development of new, or increasing severity and frequency of, challenging behaviours. These were connected to changes in routine, anxiety, lack of understanding on new public health measures (e.g., mask wearing), and a loss of connection to family and friends.
- Many families reported increased impact on their own and their families' mental health due to increased caring responsibilities, losing both formal and informal support and needing to provide 24-hour care to their relative.
- For some families there was also increased anxiety about holding on to jobs and the financial impacts of furlough and job losses.
- Several families mentioned their relative missed out on support due to challenges using technology.
- Many families mentioned not being prioritised for support, leading to a sudden drop in services and dramatic changes to family life.
- Families also commonly mentioned the need to juggle responsibilities managing home schooling for children with differing needs and looking after other family members with such significant and sudden increase in time caring for their relative.

Some families did experience some positives from the first national lockdown

- Not having to adhere to a normal routine removed the stress of daily activities such as travelling and getting ready for school which some children and young people found a challenge in daily life.
- Many families reported spending more time together doing activities which supported them building stronger relationships.
- Some families found support easier to access online with many services providing zoom calls etc where face to face meetings might have been inaccessible due to travel and replacement care needs.
- Having other family members at home for some also allowed better division of caring responsibilities and household tasks.

From the survey, a number of recommendations can be made to inform better support for this group of carers:

1. Support development and provision of information and training about challenging behaviours, both for parents and professionals in a broad range of roles supporting children and young people. Particularly needed is information and support around supporting children with learning disabilities and challenging behaviours including those with severe and profound and multiple learning disability.
2. Consider how respite provision can be increased and made more accessible for this group of families. Building on the success of wellbeing grants, alternative forms of support may be better used to provide flexible respite and wellbeing support for families.
3. Build on the good engagement of families and partnership working in schools. Families recognised good support - listen to their concerns and aims to take forward actions together to support their relative.



4. Consider the availability for support and services to young families. Earlier and easier referral processes should be encouraged for this group to connect them with support and services around behaviour at an earlier stage.
5. Support services to find time and resource to think long term about a young person's care and engage them and their family in the process. This might build on better support around EHCP plans and increased support for young people transitioning to adult services.
6. Review support and information sources to be more accessible to families. Reviving services offered by the Local Offer to ensure transparent information is offered on their ability to support this group of families and the availability of their services.
7. Whilst the study had a good reach across age groups gender and location in West Sussex, there could be further work to confirm specific barriers for non-white British families and families with children in out of area services as these groups of families may be underrepresented in survey results.

## References and Footnotes

1. Office of National Statistics (2011), UK Census, adapted for NOMIS local area profile. Available at: <https://www.nomisweb.co.uk/reports/localarea?compare=E10000032>
2. Carers UK. (2016). State of Caring 2016. Available at: <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2016#:~:text=07%20May%202016%20Carers%20UK%20carries%20out%20an,Survey%20carried%20out%20by%20Carers%20UK%20to%20date.>
3. McGill, P, Papachristoforou, E, Cooper, V (2006) Support for family carers of children and young people with developmental disabilities and challenging behaviour. Child: Care, Health & Development 32(2): 159–165.
4. Office for National Statistics. (2019). More than one in four sandwich carers report symptoms of mental ill-health. Available at: [More than one in four sandwich carers report symptoms of mental ill-health - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/peoplepopulationandcommunity/healthandcare/articles/more-than-one-in-four-sandwich-carers-report-symptoms-of-mental-ill-health)
5. We included the diagnoses of Asperger Syndrome in our survey as we felt that it would be a term that families might be aware of and use to describe their child's diagnosis. We are aware that because of its historical connotations it is often considered problematic and apologise for any offence caused in its use
6. <https://whatworkswellbeing.org/>
7. Office for National Statistics. (2021). Measures of National Well-being Dashboard. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuresofnationalwellbeingdashboard/2018-04-25>

# Appendices

## Appendix 1 – West Sussex Getting It Right logic model

Logic model - Getting It Right in West Sussex 2019-2020			
<p><b>CONTEXT:</b> In West Sussex, existing services need to be strengthened and the offer to families broadened. The CBF have experience and knowledge of supporting local authorities and CCGs and linking health with social care, education and employment. The delivery phase coincided with the coronavirus epidemic and 'lockdown', so some planned events had to be delivered online.</p>		<p><b>AIMS AND OBJECTIVES:</b> Children and young people (0-25) with learning disabilities at risk of behaviours that challenge will receive the right support, in the right place and at the right time, from well informed professionals and staff so they can live a happier and more inclusive life in their community.</p> <p>(In this logic model 'Families' refers to families of children and young people with learning disabilities whose behaviour challenges.)</p>	
<p><b>INPUTS</b></p> <p><i>Specific project inputs:</i></p> <p>National Lottery Community Funding</p> <p>GIR project time from staff at CBF and West Sussex</p> <ul style="list-style-type: none"> <li>- Children and Young People's Policy lead at the CBF</li> <li>- Policy Officer at the CBF</li> <li>- West Sussex project lead (PBS commissioning lead) and steering group</li> </ul> <p>Independent evaluation</p> <p>Financial input from W Sussex- travel and refreshments.</p> <p><i>Existing service provision in West Sussex:</i></p> <p>Children's Disability social work team/ Life Long Service; Early Help teams are SEND champions</p> <p>PBS lead commissioner supporting Special Schools</p> <p>Health challenging behaviour input through CYPRESS (under 18s), CLDT health and social care offer and access to Enhanced Support Service to cover 18-25s.</p> <p>Quarterly behaviour support network meetings for providers and families</p> <p>Special Schools have 'Team Around the School' approach.</p>	<p><b>PROCESSES</b></p> <p>GIR steering group meetings</p> <p><i>To inform delivery plan:</i></p> <p>2 x family carer focus group (North and South)</p> <p>Stakeholder (professionals and family carers) event in West Sussex</p> <p>Online survey of family carers and professionals about the service provision in W Sussex</p> <p>CBF write up findings in report and co-produce delivery plan for W Sussex.</p> <p><i>To develop families' and professionals' skills and confidence in PBS:</i></p> <p>1x 3 positive behaviour support workshops.</p>	<p><b>OUTPUTS</b></p> <p>Meaningful plans for sustainable improvements in support in West Sussex</p> <p>Provision of specialist training and sharing of best practice with families, commissioners, and professionals in West Sussex.</p> <p>New self-sustaining networks established to support families, informed by focus groups/survey.</p> <p>Families have a space (in focus groups in the first instance and then virtually) to share their experiences/feel listened to by services and each other.</p> <p>Presentation on project findings by West Sussex colleagues at Challenging Behaviour - National Strategy Group Meeting.</p>	<p><b>OUTCOMES</b></p> <p><b>KEY OUTCOME:</b> Families are more resilient.</p> <p>Families have the knowledge and confidence to use PBS techniques to understand reasons for challenging behaviour and to respond appropriately.</p> <p>Families who have been on PBS workshops find a reduction in the prevalence/severity of challenging behaviour and positive changes to the whole family dynamic.</p> <p>Families feel well informed about useful services and support in West Sussex.</p> <p>Families are routinely involved as valued co-producers in developing and improving services and support.</p> <p>Families feel less isolated and better connected to local support networks.</p> <p>Professionals learn from families (through this project and beyond) and use learning to strengthen support and services they are offering.</p>

## Appendix 2 – Getting it Right in West Sussex survey questions

Q1. What is your relationship to the child or young person you have caring responsibilities for?

### Answer Choices

My Child  
My Sibling  
My Grandchild  
My Niece or Nephew  
My Foster Child  
Other (please describe)

Q2. Please type in the first 3 or 4 digits of your postcode ( ie BN6, RH20 etc. this will not be used to identify you)

Answered  
Skipped

Q3. What is your age?

Answered  
Skipped

Q4. Which description best describes your ethnic background? (Please choose only one)

### Answer Choices

White/White British  
Black/Black British  
Asian/Asian British  
Mixed race  
Rather not say  
Another race or ethnicity (please specify)

Q5. Do you have caring responsibilities for any other member of your family or household?

### Answer Choices

I care for an older parent or grandparent  
I care for another child under 5  
I care for another child over 5  
I care for another member of my household or family with a disability  
I have no other caring responsibilities

Q6. Please tick any of the following statements which apply to the disabled child you care for. You can tick as many as apply. My relative has:

### Answer Choices

been diagnosed with a learning disability  
been diagnosed with a severe learning disability  
been diagnosed with a profound and multiple learning disability  
been diagnosed with autism  
been diagnosed with aspergers syndrome  
a suspected learning disability (but no diagnosis)  
suspected autism (but no diagnosis)  
A complex additional physical health condition  
Other (please explain in your own words)

Q7. How long have you been waiting / did you wait for a diagnosis of your relative's condition?

### Answer Choices

under a month  
1- 3months  
4-6 months  
6 months to a year  
Over a year  
Comments

Q8. How old is your relative?

Answered  
Skipped

Q9. Is your relative?

Answer Choices

Female  
Male

Q10. How does your relative communicate (please tick all that apply)

Answer Choices

Verbal, using speech  
Using own gestures or a signing system like language/Makaton  
Using a picture system like Picture Exchange Communication or photobook  
Using objects of reference (eg using a cup to indicate thirst or getting shoes if they want to go out)  
Using just body language  
Using other alternative or assistive forms of communication support eg electronic aids (please explain here)

Q11. Does your relative:

Answer Choices

Live at home  
Live away from home (please specify where)  
Does a mixture of both ( please specify where)  
Tell us about your relative's living arrangements here ( this information will not be used to identify you)

Q12. Does your relative behave in ways that challenge you or others around them?

Answer Choices

Never  
Sometimes (e.g. every month or so)  
Most weeks  
Once or twice a week  
Daily

Q13. How old was your child when they first began to display behaviour that is challenging?

Answered  
Skipped

Q14. What impact does the behaviour have on your ability to access services like your GP or community facilities like parks and libraries?

Answer Choices

Very Negative Impact (unable to attend school and access normal activities at all)  
Negative Impact (can access some activities but most are inaccessible)

Significant Impact (can access many activities but some are very difficult)  
Some Impact (some activities are hard to access but overall we can access most things)  
No Impact (my child can access everything they need/ want to)  
Comments

Q15. What impact does the behaviour have on your relative?

Answer Choices

Very Negative Impact (they experience significant physical or emotional harm)  
Negative Impact (they experience physical or emotional difficulties which are hard to manage)  
Some Impact (they experience moderate physical or emotional difficulties which are able to be managed)  
Slight impact (they experience mild physical or emotional difficulties which are easy to manage)  
No Impact (they experience no physical or emotional difficulties due to their behaviour)  
Comments

Q16. What impact does the behaviour have on your family?

Answer Choices

Very Negative Impact (physical injury or mental health problems in family members)  
Negative Impact (physical or emotional difficulties that are often difficult to manage)  
Some Impact (physical or emotional difficulties which are sometimes difficult to manage)  
Slight Impact (physical or emotional difficulties which are easily managed)  
No Impact (no physical or emotional difficulties are experienced as a result of behaviour)  
Comments

Q17. Have you asked for help with your relative's behaviour?

Answer Choices

Yes  
No

Q18. If yes, who have you approached for behaviour support? (Please tick all that apply)

Answer Choices

Portage  
Nursery  
School or College  
GP  
Specialist CAMHS LD/ Challenging behaviour team (now called CYPRESS)  
Community learning disability team  
Early Intervention Team working with an Early Help Plan  
Paediatrician  
Health Visitor  
CAMHS  
Social Communication Team  
Learning Behaviour Advisory Team  
Other (please specify)

Q19. Did you receive any support?

Answer Choices

Yes ( please give details in box below)  
Some (please give details in box below)  
No

Comments ( please use this space if you would like to share any experiences you may have about accessing any of the above services )

Q20. How long did it take to receive behaviour support?

Answer Choices

- under a month
- 1- 3 months
- 3-6 months
- 6 months to a year
- More than a year
- Comments

Q21. How happy were you with the support you received?

Answer Choices

- Very happy
- Happy
- No strong feelings either way
- Unhappy
- Very unhappy
- Comments

Q22. What tools and strategies do you use to manage your child's behaviour?

Answer Choices

- A Postive Behaviour Support plan
- A Visual Timetable
- Putting in place a regular routine
- Sensory Play
- Specialist communication tools like PECS
- Other (please specify)

Q23. If you do not use any of these tools what are your main reasons for not using these approaches?

Answer Choices

- They don't meet my relatives needs
- I haven't been offered them
- I don't know enough about them to understand how they might work for my relative
- I am not confident in how to use them
- Other (please specify)

Q24. How easy is it for you to access information on the following?

I have not needed/ tried to access	Not able to access at all	Information is hard to find	I can find some information	Information is fairly easy to find	There is a lot of information very easily available
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- Supporting a child with learning disabilities
- Supporting a child with autism
- supporting a child who displays challenging behaviour
- Financial support
- Practical support for families of disabled children
- Support and services available in West Sussex
- Keeping in touch with other families
- Looking after my own needs as a carer

My rights and the rights of the child I care for  
Please let us know of other information needs you have

Q25. If you have accessed information on the following how would you rate its quality?

I have not accessed information	Very Poor Quality	Poor Quality	Reasonable Quality	Good Quality	Very Good Quality
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Supporting a child with learning disabilities  
Supporting a child with autism  
Supporting a child who displays challenging behaviour  
Financial support  
Practical support for families of disabled children  
Support and services available in West Sussex  
Keeping in touch with other families  
Looking after my own needs as a carer  
My rights and the rights of the child I care for  
Please let us know if you feel there are particular gaps in quality information here

Q26. How do you prefer to get information? (Tick as many as apply)

Answer Choices

Websites  
Facebook  
Printed material/leaflets  
Other social media  
Email  
Over the phone  
Face to face from other families  
Face to face from professionals  
Other (please specify)

Q27. Does your relative usually (outside of the Covid-19 restrictions) attend a nursery, school or college?

Answer Choices

Yes  
We are awaiting a placement  
We home educate  
No

Q28. Which nursery, school or college does your relative attend? (This information will not be used to identify them)

Answered  
Skipped

Q29. How well do you think the nursery/school/college is managing your relative's behaviour?

Answer Choices

Very well  
Quite well  
No strong feelings either way  
Less well than hoped  
Not well at all  
Comments ( Please use this space if you'd like to tell us more about your experiences of managing behaviour at school, college or nursery)



Q30. How well does the nursery, school or college listen to and work with you as a carer to address your relative's behaviour?

Answer Choices

Very well

Quite well

No strong feelings either way

Less well than hoped

Not well at all

Comments ( Please use this space if you would like to tell us more about how the school, college or nursery work with you as a carer)

Q31. Have you heard of the West Sussex Parent Carer Forum?

Answer Choices

Yes

No

Q32. Are you a member of the forum?

Answer Choices

Yes

No

Q33. How useful do you find the forum?

Answer Choices

Extremely useful

Very useful

Somewhat useful

Not so useful

Not at all useful

Comments

Q34. Have you heard of Carer Support West Sussex?

Answer Choices

Yes

No

Q35. Have you used the services of Carer Support West Sussex?

Answer Choices

Yes

No

Q36. How useful do you find the support offered by Carers Support West Sussex?

Answer Choices

Extremely useful

Very useful

Somewhat useful

Not so useful

Not at all useful

Comments

Q37. Have you heard of the Local Offer?

Answer Choices

Yes  
No

Q38. Have you used the Local Offer?

Answer Choices

Yes  
No

Q39. How helpful did you find the local offer?

Answer Choices

Extremely useful  
Very useful  
Somewhat useful  
Not so useful  
Not at all useful  
Comments

Q40. Have you heard of the SENDIASS service? (It used to be the Parent Partnership)

Answer Choices

Yes  
No

Q41. Have you used the SENDIASS service?

Answer Choices

Yes  
No

Q42. How useful did you find the service?

Answer Choices

Extremely useful  
Very useful  
Somewhat useful  
Not so useful  
Not at all useful  
Comments

Q43. What one thing would improve these services (West Sussex Parent Carers Forum, Carers Support West Sussex, the Local Offer, SENDIASS) to support you better in the future?

Answered  
Skipped

Q44. Overall, how satisfied are you with your life nowadays?

Answer Choices

Sliding scale from 1-10

Q45. How confident do you feel in your ability to provide the right care to your relative?

Answer Choices

Extremely confident  
Very confident  
Somewhat confident

Not so confident  
Not at all confident  
Comments

Q46. Have you had a Parent Carer Needs Assessment (PCNA) or a Carers Assessment (if you child is over 18)?

Answer Choices

Yes  
It was included in my child's assessment  
I am waiting for one to be carried out  
No  
Not Sure

Q47. If you get overwhelmed with your role as a carer what support do you feel would help you to manage your own wellbeing?

Answered  
Skipped

Q48. How well supported by services like carers groups , community groups and health and social services do you feel the other members of your family are to manage their caring role and wellbeing?

Answer Choices

Very well  
Quite well  
No strong feelings either way  
Less well than hoped  
Not very well at all  
Comments

Q49. What support would help your family manage their own needs as carers?

Answered  
Skipped

Q50. Do you know about the Parent Carer Health & Wellbeing Grant administered by West Sussex Parent Carers Forum?

Answer Choices

Yes  
No

Q51. If you've received a grant, how was it helpful to your wellbeing and resilience?

Answer Choices

I have not received a grant  
I have received a grant  
If you have received a grant use this space to tell us how it helped you

Q52. Would you like to know more about the grant? (To receive an email including details please leave your details at the end of the survey)

Answer Choices

Yes  
No

Q53. Has Covid-19 and the lockdown restrictions had an impact on how often your relative displays challenging behaviours?

Answer Choices

Much less often  
Slightly less often  
No change in frequency of behaviour  
Slightly more often  
Much more often  
Comments

Q54. Has Covid-19 and the lockdown restrictions increased the severity of your relative's behaviour?

Answer Choices

Much less severe  
Slightly less severe  
No change in severity of behaviour  
Slightly more severe  
Much more severe  
Comments

Q55. Has you relative developed any new behaviours during Covid-19 and lockdown restrictions?

Answer Choices

No  
Yes (please specify)

Q56. Why do you think any changes in behaviour have happened?

Answered  
Skipped

Q57. What negative impact has Covid-19 and the lock down restrictions had on the day-to-day life of your relative?

Answered  
Skipped

Q58. What postive impact has Covid-19 and the lock down restrictions had on the day-to-day life of your relative?

Answered  
Skipped

Q59. What negative or challenging impacts have your felt from Covid-19 and the lock down restrictions on you as a carer and your wider family?

Answered  
Skipped

Q60. Has Covid-19 and the lock down restrictions had any positive outcomes for you as a carer and your wider family?

Answered  
Skipped

Q61. Can you describe briefly your hopes and ambitions for your child's future?

Answered  
Skipped

Q62. What, if anything, makes it more difficult to achieve those hopes and ambitions?

Answered  
Skipped

Q63. What, if anything, would help to achieve those hopes and ambitions?

Answered  
Skipped

Q64. Overall how listened to do you feel as a carer by professionals caring for your relative in planning for their future?

Answer Choices

Very listened to  
Often listened to  
No strong opinion either way  
Not often listened to  
Not listened to at all  
Other (please specify)

Q65. Overall how supported do you feel by the professionals supporting your relative in making these plans a reality?

Answer Choices

Very supported  
Quite supported  
Neither supported nor unsupported  
Less supported than I would like  
Not very supported at all  
Comments

Q66. Please enter your name and email address below

Answer Choices

Name:  
Email Address:

Q67. Please select what you would like your information to be used for

Answer Choices

Please enter me for the amazon card prize draw  
I would be interested in being interviewed as part of the project  
I would like to receive updates on the project and the findings of this survey  
I would like to receive an email about support and services I might find useful

### Appendix 3 – Notes on significance and survey analysis

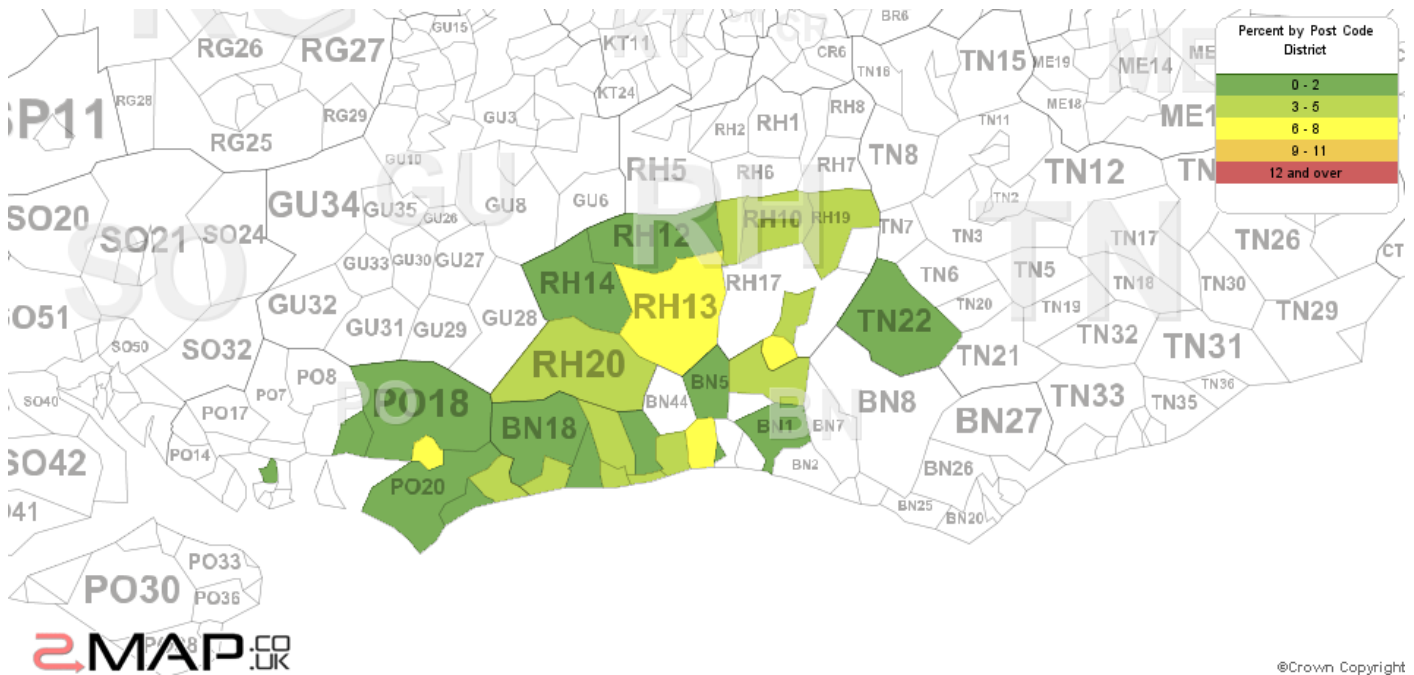
Comparisons between groups of respondents in this report were made and analysed using contingency/cross tab tables and chi squared analysis to determine if the differences observed between groups could represent a significant difference in populations.

Due to some categories being represented by small samples sizes Fishers Exact test was used and significance compared to determine relevancy of results.

Where differences between different groups of carers are reported in this report, they are followed by a p value in brackets to indicate how significant this finding is in relation is in relation to what we would expect to see generally in the survey population. The lower the p value the more reliable the finding is likely to be. In this report we have taken a significance of  $p < 0.05$  generally to be the maximum at which results will be seen as significant enough to report with a reasonable level of certainty. This is in line with much social research reporting especially when working with smaller sample sizes where higher values are often observed. Due to the very small sample sizes, a very small number of results have been cautiously reported at  $p < 0.1$ . Where results fall into this more uncertain category they have been included in the report as “there being some evidence” and the exact p value has been stated in brackets.

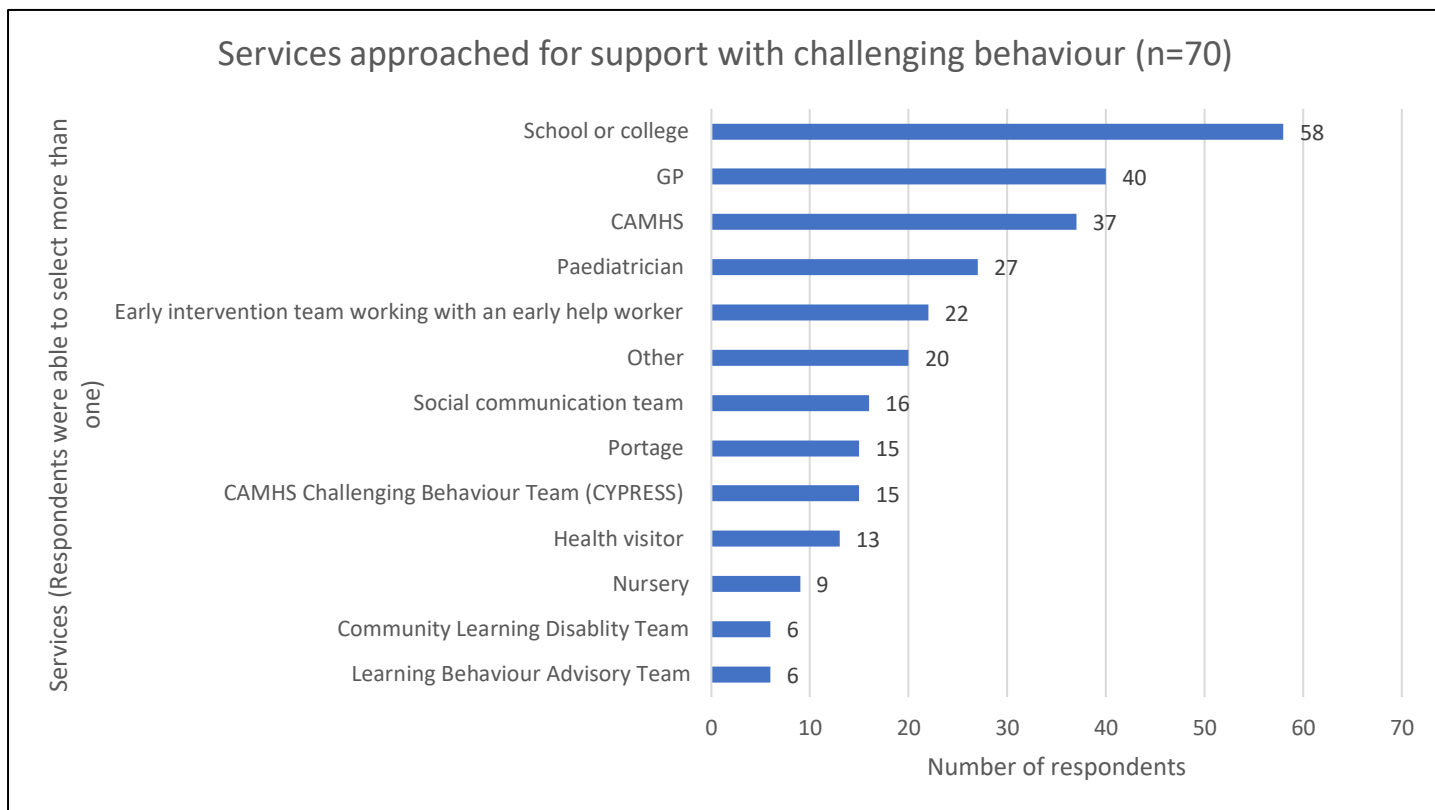
## Appendix 4 – Geographical spread of West Sussex respondents

Made using 2map.co.uk



A map to represent the geographical spread of respondents across West Sussex

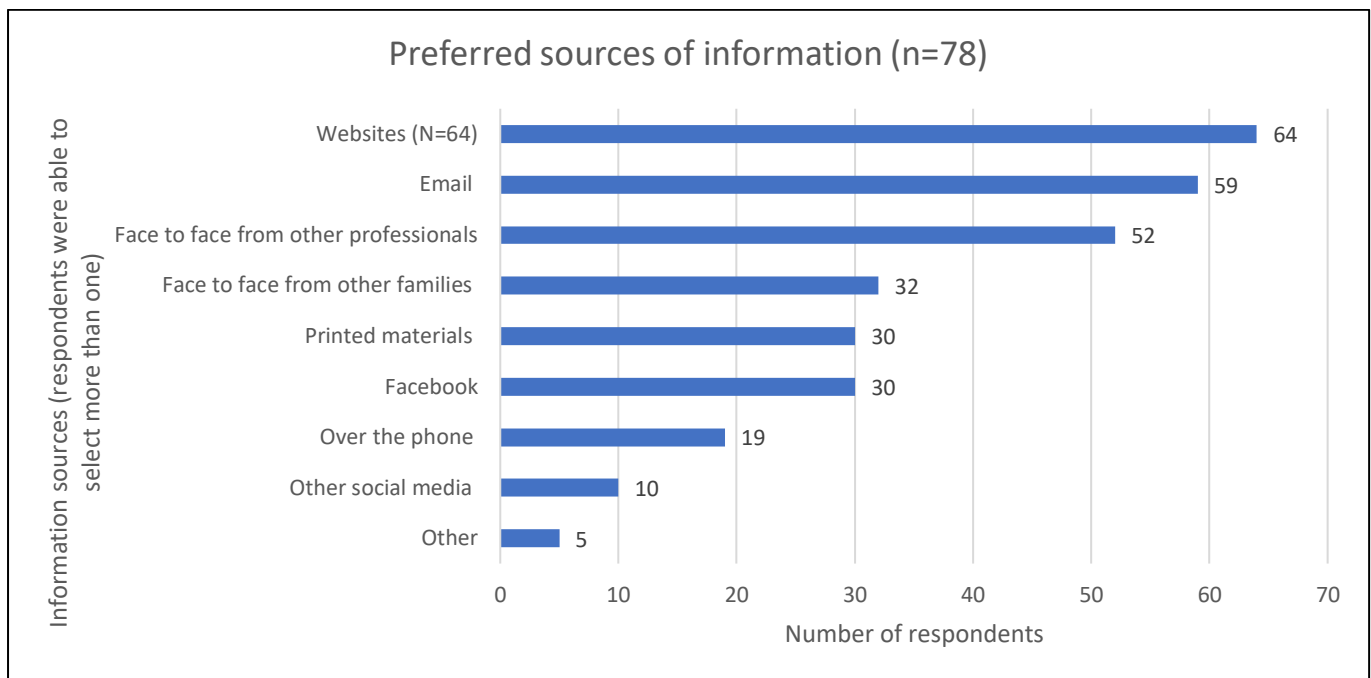
## Appendix 5 – Services approached for support



Graph to show the services approached by families for support with challenging behaviour



## Appendix 6 - Graph showing respondents' preferred source of information



Graph showing the different methods and sources that families preferred to receive information from