# Parent Carers' Information Needs Survey 2021

We wanted to know whether parent carers are getting the SEND information they need from Amaze, and whether our information is in formats and media parent carers find useful.

# Method

We asked parent carers in Brighton & Hove and East Sussex to complete a detailed **survey** via our newsletter, website and social media channels. The survey was also shared in the WhatsApp groups run by our Face 2 Face project, and the local parent carer forums, PaCC and ESPCF

Our Communications Manager also attended three **parent carer Zoom groups** in Brighton & Hove to gather views about information needs more informally.

# The survey

We had 94 responses in total, **69 complete** and 25 partial.

## About the respondents

* **Location:** We had roughly the same number of responses from Brighton & Hove and East Sussex parent carers (around 40% each) with just under 20% from West Sussex.
* **Gender:** 56 people answered this question and 55 identified as female, one person as Other.
* **Age range:** Over 50% were aged 35-49. 26% were aged 50-59 and 14% 25-34.
* **Ethnicity:** 57 people answered questions around **ethnicity**. 53 (93%) identified as white British, 2 (3.5%) as any other white background and 1 (1.8%) as Mixed white and Asian. One preferred not to say.
* **Language:** Only 4 of the respondents had English as an additional language and they could all read English

A full interactive survey report can be viewed at [Alchemer - Report on Parent Carers' Info Needs 2021](https://reporting.alchemer.com/r/91359_61e7e1d2080909.05802636)

Potential actions identified from answers to the survey are in **green text**

For information on our Focus Groups skip to the accompanying Focus groups document

# What information do parent carers want?

We asked parent carers identify the five SEND topics they needed need more information about from a list of 11. They could also select ‘all’.



Their responses indicate that the main areas of interest are **SEN services** (inc Amaze’s), **SEN support in school** and **inclusive leisure**. Note that info about specific conditions scores quite low.

*ACTIONS:*

* *We may wish to consider returning to providing information about inclusive leisure, as we used to do in the ‘Fun Things To Do’ fact sheet.*
* *We may also want to consider not devoting too much energy towards creating Amaze information on specific conditions.*

We also gave them space to suggest other SEND issues not listed that they would like to get more information about. Repeated suggestions included **more information about respite** and **social care**; **sibling support**; **planning for the future** including transition, employment, housing, power of attorney and education; **school transition** and **attendance** and **mental health. *\*See Appendix 1 for full details***

# When do parent carers most need information?

We asked parent carers to tell us about all the stages on their journey when they needed information the most. Key moments identified were when trying to get the right **support in school** and during the **assessment/diagnosis** process, though the need was fairly evenly spread across all life events.

**Parents who selected ‘other’ added:**

* *“All the above - different levels of support depending upon what information was freely accessible. This is a hard journey which has no bearing on caring for the young person but accessing the right support and each developmental stage has been tough. And something I try to forget about when moving onto the next hurdle.*
* *“Foster Carer so information when child placed”*
* *“How to manage problems/behaviour due to autism”*
* *“Waiting for assessment/diagnosis”*
* *“When I felt there was nowhere to turn”*
* *“When by child became very unwell - mental illness at primary school”*

# Where do parent carers go for information about SEND?

Parent carers primary sources of information about SEND were the Amaze website, Google and friends or support groups. Note that only 25% said they used our helpline for information, which may suggest our messages to use website first are working. Also note the very low score of Local Offer.

Respondents who ticked ‘Other’ added:

* *Autistic adults*
* *CAMHS adoption support worker*
* *CLASS + and ESPCF*
* *Facebook group for her specific chromosome deletion*
* *National organization*
* *Other parents and charitable organisations*
* *Social worker and lead practitioner*
* *Supportive parent/carer-led social media groups*

*ACTIONS:*

* *The high percentage of parent carers who use the Amaze website to get information about SEND suggests that focusing on improving the site’s content and design would be a sensible use of resources.*

# How do parent carers prefer to get their information?

We asked parent carers to tell us all the ways they liked to get SEND info and then to rank them from their favourite to least favourite.

|  |  |  |  |
| --- | --- | --- | --- |
|  | Rank  | Score  | Total Respondents  |
| Read online  | 1  | 314  | 76  |
| Read in print  | 2  | 266  | 76  |
| Get info from another person  | 3  | 247  | 76  |
| Watch a video  | 4  | 175  | 76  |
| Get info via text or WhatsApp  | 5  | 138  | 76  |

Reading online was clearly the most widely used way of getting information (76%) and over 50% of respondents also asked another person or read stuff in print. Interestingly, only 34% of respondents liked to watch videos for SEND information and it was ranked 4th in preference.

*ACTIONS:*

* *Though one of our strategic goals is to create more informational videos, we should be mindful of the resources spent on this versus popularity*

# Using Amaze as a source of information

82 percent of the respondents had used Amaze as an information source.

## If not using, why not?

We wanted to know more about why some families don’t use Amaze for their SEND information.

13 respondents (17.8%) said they hadn’t used our services. These were their reasons:

|  |  |  |
| --- | --- | --- |
| **Why?** | **Percent**  | **Count**  |
| I didn't know about you  | 7.7%  | 1  |
| I'd heard of you but I wasn't sure what you could help with  | 61.5%  | 8  |
| I don't need any help with my child's SEND right now  | 15.4%  | 2  |
| I'm nervous about asking for help  | 38.5%  | 5  |
| I don't live in the area that Amaze serves  | 7.7%  | 1  |

The two main reasons cited therefore are not understanding our offer and feeling anxious.

*ACTIONS:*

* *We could focus on simplifying the way we present our offer and spread the word about who and how we can help more effectively.*
* *We may also need to consider how to reach out to more vulnerable/anxious parents.*

# Which Amaze’s information resources do parents like and use?

We asked parent carers to tell us about all the Amaze resources they use or have used, and then to rank them from favourite to least favourite.

|  |  |  |  |
| --- | --- | --- | --- |
| Item  | **Overall Rank**  | Score  | Total Respondents  |
| Amaze website  | **1**  | 284  | 58  |
| Amaze helpline  | **2**  | 215  | 56  |
| Out of Amaze e-newsletter  | **3**  | 215  | 54  |
| Amaze social media channels  | **4**  | 209  | 56  |
| Compass e-bulletin  | **5**  | 144  | 53  |
| Compass social media channels  | **6**  | 114  | 53  |

Parent carers who ticked ‘Other’ added:

* Amazing futures
* Buddy
* leaflets from school and groups

Once again, parent carers say they most like to get information from Amaze via our website, with the helpline and newsletter equally valued as an information source, followed by social media. The Compas Ebo scores may be artificially low because many respondents (40% from East Sussex at least) would not be eligible.

Action: More confirmation of the importance of the website as an information source.

# What about the Amaze newsletter?

25 respondents told us they receive our newsletter by email. We asked them to tell us whether they read it sometimes, always, rarely or never.

There were no ‘rarely’ or ‘never’ responses. These results may well be skewed by the digital nature of the survey. Not surprisingly, parent carers who are comfortable reading and interacting with an online survey, may also be happy reading a digital newsletter.

We also wanted to interrogate whether the newsletter went into their spam box or junk. Encouragingly, 92% (23) respondents said it went into their Inbox. 2% into spam.

ACTION: Lower opening rates probably shouldn’t’ be ascribed to emails going into spam

# 8. Social media - do our parent carers use social media?

93 percent of the respondents told us they use social media. We asked them to tell us which social media channels they use.

## Do our parent carers follow Amaze on social media?

84 percent of 68 respondents said they followed Amaze on social media, using the following channels:

It’s clear that **Facebook is still the preferred social media platform** for our parent carers both in general terms and for Amaze social media specifically. **Instagram** is the second most popular in general but the fourth most popular Amaze channel.

*ACTION: In addition to focusing on Facebook, we could shift some of our social efforts effectively from Twitter to Instagram.*

Likewise, 34% of respondents liked using Youtube generally but only 7% used Amaze’s Youtube Channel.

*ACTIONS:*

* *The gap between Youtube popularity and people’s knowledge/use of Amaze Youtube suggests we could devote more energy to improving and publicising our Youtube presence.*
* TikTok is probably a waste of time for parent carers.

## How often do parent carers see Amaze’s social media posts?

Recent changes to the algorithm that underpins Facebook has meant a drop in our Facebook user engagement, despite an ever-growing audience. We have been concerned that families were not seeing our posts or not seeing them regularly.

Encouragingly, only 12% of our social followers say they see our posts Rarely or Never.

# What would improve Amaze’s SEND information?

30 parent carers answered this optional question and their suggestions were really varied and helpful. Seven said they’d change nothing or were happy with our info. These were the others’ suggestions/requests:

* *Something personal to my child*
* *More information aimed at young adults aged 20*
* *Better access for people who live in East Sussex as I was initially under Brighton and Hove moving over to East Sussex has been difficult for accessing services*
* *I feel it's a wonderful wealth of information but feel they should advertise more about services they can provide*
* *Nothing, but I do prefer a printed copy of it as I digest the information more easily.*
* *More of a diagram layout*
* *Easier to access for parents who don't already know about you. I had to do a lot of searching to find u*
* *Difficult to get fast reply to sen advice. Need seperate ehcp support caseworkers to apply forr one and monitor ehcp support in school.*
* *A quicker turn around time on phone calls. Not a criticism though.*
* *Make it easier to access by putting it in diagnosis or need category so it's easier to find.*
* *More helpline workers*
* *To include more about childhood trauma and support*
* *Being able to speak to someone when I ring the helpline*
* *Over the years I've found amaze so helpful. I would like to see more information for young people with complex mental health diagnosis combined with autism or learning disability. There's no information on care education and treatment reviews - what they are, who they are for etc., I researched it myself and read the information published on NHS England. I do feel there is a gap. I don't know anyone who has gone through this, and felt sure Amaze didn't (nothing published) so I didn't get in touch based on that*
* *More relevant to whole of ESCC, no so Brighton based re workshops etc*
* *I wish there could be more support groups in and around Heathfield. I find it very difficult to travel to Brighton.*
* *More local info parents contact transition adulthood*
* *More specific info about conditions/diagnoses on website*
* *To be less focused on Brighton and Hove and include more information from the rest of East Sussex.*
* *Clarity and depth*
* *Be signposted as a service as part of the form you have to sign as part of agreeing to putting your child on the register.*
* *More information on services and funding. What is available.*
* *Easier access when trying to speak with someone*

## **Appendix 1.** What kinds of information do individual parent carers need?

|  |  |
| --- | --- |
| Social care* respite/PA
* Recruiting a PA and Direct Payment criteria
* Suppliers for specialist equipment, such as rnib for visually impaired school supplies
* Can the Sen funding be used for therapeutic work
* Social care and home to school transport
* Social care and social care law
* Respite care
 | Support and groups* Springboard & kangaroo groups
* Siblings support
* Couples support/ therapy
* Local sen support groups
* Help for siblings of SEND children
* I wish there was more support in rural areas. We are always at least 15-20 miles from the nearest support group.
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| Planning for the future* Housing options for my child's future
* Power of attorney
* What the future holds For both myself as a parent/carer and the young person?
* What education provision there is post 16
* On going contact with other parents post 25 maybe
* Residential including respite services. Supported housing post-18.
* Transition service post 20
* Transition to adulthood (couldn't tick it)
* Finding jobs for teenagers with SEND
 | Education* Transfer between primary to secondary schools
* Finding a school around my sons needs
* Non school attendance
* Transition from primary to secondary school, which secondary schools offer the best for SEN and information on transitioning from child to teenager
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| Diagnosis and ongoing treatment* Routes to diagnosis, and how different diagnoses can affect the support offered
* More sensory inputs how to get a child to focus more and help alleviate fears and anxiety
* Diet and weight issues for children with sen
* FASD
* How different mental health conditions present themselves in neurodivergent people
* Mental health, Collaboration of services and joint working to support child
* Coping with behaviour
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