amaze helping you through for families with disabled children and young people in Sussex

NHS England & Improvement Commitment to Carers

Rapid-learning pandemic legacy projects

1. Executive summary

This research looks at how the Covid-19 pandemic, and related lockdowns and restrictions, have exacerbated pre-existing difficulties and health, social and economic inequalities, and created lots of new uncertainties and obstacles for children and young people (CYP) with special educational needs and disabilities (SEND) and their parent carers.

Many families had to shield at home for long periods during lockdown, which led to increased social isolation and worsening mental health for the family. CYP's education has been significantly disrupted with schools struggling to provide their usual level of support, and CYP experiencing increased anxiety about returning to the classroom.

Parent carers told us how they experienced high levels of confusion, frustration and anxiety about the Covid vaccine programme both for themselves, and for their children. In particular about changing eligibility criteria, in trying to seek details about possible reasonable adjustments and in staff's lack of understanding about learning disability and neurodevelopmental conditions.

Disabled children have also been unable to access pre-pandemic levels of therapies, respite care and health services. As support has been taken away, parents have been left feeling overwhelmed and exhausted, and it is no surprise 70% of parent carers tell us they have experienced mental health problems.

More families have fallen into debt, are having to rely on food banks, and are making applications for (disability) benefits – often for the first time - as parent carers had to take unpaid leave or give up work to care for their children. This is on top of the disproportionate impact of rising fuel prices on disabled families, and the Universal Credit uplift being withdrawn.

Amaze is the go-to charity in Brighton and Hove and East Sussex for parent carers, providing a wide range of information, advice and support. Amaze responded quickly to the CV19 crisis, developing a range of parent carer specific Covid-19 FAQs and web pages – translating often very complicated government guidance, into more readable information, specific to the needs of our local community - https://amazesussex.org.uk/coronavirus-advice/. These pages had over 20,000 page views during the year and helped us attract over 52,000 new users to our website.

While calls coming into our Advice Line were slightly lower in the first lock down, as carers struggled to cope having their disabled child(ren) at home 24/7, this soon picked back up and we are experiencing higher levels of demand than ever before across all our services. For instance, our Advice Line responded to over 3,600 enquiries from about 3,000 individuals and we supported nearly 600 families claim DLA/PIP last year. Our established one-stop-shop model meant we could

quickly identify and meet a wide range of needs, and having a high proportion of parent carer staff, and close links to the local parent carer forums, meant we were able to quickly identify new needs arising from the pandemic, and offer solutions to these.

However, this evaluation has shown us that not everyone knew/understood what was available via our revised digital offer, had the capacity to reach out to us, or were happy when waiting times increased. But carers felt that we listened to them and appreciated our focused attempt to proactively reach out to the most isolated families during the lockdowns. They also appreciated our supporting (lobbying) other services to change/improve their practice, but Amaze needs to consider how to better communicate the other things it does.

We also asked what parent carers views were about the responsiveness of other key services for their children, including schools. While carers identified some good practice, there were a large number of reported frustrations and dissatisfaction with reductions or stopping of provision across the system.

It is clear everyone has been working under exceptional pressure, and we want to thank local teams and services who have worked incredibly hard during this time. We hope each will take some time to read this report and use it with their teams to reflect on the parent carer feedback and recommendations that we can each take forward, to improve our combined service offer to CYP with SEND and their parents and carers, both now and how we respond to future crises.

2. Method/Process

We wanted to find out:

- How the pandemic most impacted parent carers and their child or young person with SEND
- If services reached out to them to ask them what they needed, or offer support, and their feelings of isolation
- If services were available/accessible during the pandemic
- To specifically ask about perceived accessibility and take up of the Covid vaccines
- How much they felt their views had been sought, or listened to throughout
- If families liked how services developed their digital offer
- What more Amaze, or other services, could have done to help during the pandemic and going forwards
- What we can learn from the experience that could help improve things in the future for parent carers and their CYP with SEND.

We co-produced the research framework with parent carers. We ran two main surveys focusing on the impact of Covid during February 2022 and received responses from 141 parent carers and 57 professionals, living or working with CYP with SEND in Sussex. In addition, we held focus groups with groups of parent carers attending the Brighton Sunflower Support Group (based in Moulsecoomb), the Eastbourne Face to Face group and with Face-to-Face befrienders. We gathered feedback at the Brighton & Hove PaCC Awards event and carried out an internal focus group with the management team at Amaze.

We also worked in partnership with the three Sussex parent carer forums, and with support from Brighton and Hove Public Health, to specifically evaluate the Covid vaccine roll out: looking at the take up for parent carers, as well as clinically extremely vulnerable CYP, identifying any ongoing barriers/concerns parent carers might have. Our survey was co-designed and had three strands to reach specific target groups:

1. Carers who wanted vaccination for themselves or a child or young person and had been unable (at that stage) to achieve this
2. Carers who declined vaccination for one or more of their children
3. Carers whose child or young person had been vaccinated

Strand 1 was run early so it could best inform local work on access to vaccination. Strands 2 and 3 were carried out later, once the vaccination offer was wider. Each strand was sent to c.1200 parent carers in Sussex as well as being shared via Amaze social media. The aim was to get focussed feedback from targeted groups rather than expecting high numbers of responses. 104 parent carers responded about 154 CYP.

The surveys captured views from parent carers of CYP with a wide range of additional needs (including autism, ADHD, learning disabilities, physical disabilities, long term medical conditions and mental health) and heard from professionals working across a range of agencies, including local authority, social care, early years and health teams, schools, Amaze and other voluntary sector staff.

In addition to the survey responses, where relevant, we have added findings from other research/surveys undertaken by Amaze over the last two years, as well as drawn on the content of queries to our advice line service and feedback made in comments on our social media posts.

3. Key findings

Our main aim in doing this research was to improve our understanding about how best to provide support to parent carers, so they will ultimately benefit from an improved service offer from both ourselves, and our partners working across Sussex.

Though the focus of our research was on the needs of parent carers, we know that their wellbeing and resilience is much improved if the care and support for their child(ren) with additional needs is in place. As such, many of these findings, and our reflections and recommendations for shared learning, concern improving provision for CYP with SEND, which in turn reduces parental carer anxiety and exhaustion.

A full set of survey results and analysis is available to read in our below. *Note: quotes received from parent carers or professionals are in “blue italics”.*

A summary of our main findings is included here.

a) Parent carers are exhausted from the added pressures of the last two years. Not enough respite was available.

70% told us their levels of fatigue and exhaustion were much worse – caused by the challenges of caring 24/7, and not having many/any breaks from their child(ren).

Many parent carers reported their short breaks service closed or reduced and they found it impossible to find other sources of respite. Time in school is a source of respite for parent carers.

So school closures removed a key source of respite. Even where CYP were allocated a place in school, Covid control measures as well as ongoing staff shortages meant that many children were out of school for extended periods.

"We should have given parents more of a break from their caring role but this would have broken government guidance…"

b) High levels of stress and anxiety led to poorer health and wellbeing:

80% and 66% respectively said their 'confidence' and 'other mental health issue' had got worse.

75% said their physical health had worsened.

Covid-19 has caused a high degree of anxiety and worry to both CYP with SEND and their parent carers. Parent carers have been worrying more about a lot of issues: how best to keep their family safe, the reduction of services to support their child's needs, how to attempt home schooling while trying to keep their job, worsening household finances, isolation/loneliness etc. With so many other worries, parent carers had no time left to look after their own physical and mental health.

Some parent carers reported that their children had benefitted from a more relaxed routine at home during the lockdowns, without the pressure to attend school, or if they had attended – they had benefitted from the smaller class sizes and extra support from teachers. While good at the time, this made for a harder transition back to school, or as other pupils returned.

More CYP have experienced worsening mental health as they have been forced out of their previous routines, isolated from their peers, and are scared about catching the virus (and may have experienced the loss of a family member).

The already lengthy waiting lists for services, such as CAMHS, has increased, leaving many parent carers supporting very vulnerable CYP on their own, sometimes with very significant mental health needs.

Huge delays to assessments e.g., three years for ADHD in some areas, can mean that a child's needs aren't being met in school and elsewhere with long-term impact on their education and wellbeing, with children at risk of falling out of education or becoming emotional based school refusers.

There are also issues with CYP masking their needs, in girls in particular, and mental health issues such as eating disorders or self-harm being the first sign that they might have a neuro-diverse condition.

"Family mental health went down, son became more closed off, no access to mental health support through CAMHS".

A high proportion of early Covid deaths were disabled people but the data got mixed with "health conditions" so was not analysed as such. It took a long time to recognise and address the increased risks for some disabled groups – for instance young people with Down syndrome. Also, there was an early issue with 'do not resuscitate' for people with learning disabilities, severely damaging trust among that community. The focus on medical conditions associated with increased Covid risk - but not disability - meant some services, shops etc failed to plan, and put in place, reasonable adjustments.

Some respondents highlighted that the Brighton and Hove's local walking and cycling infrastructure plan during Covid did not take care about disabled people and ended up closing Blue Badge spaces along Brighton Seafront so people could not access the Changing Places toilets.

c) **Parent carers became more <u>isolated</u>, as many were shielding clinically vulnerable children for much longer. There was not enough proactive support or outreach to help**, or recognition of the added challenges they faced with disabled CYP at home for longer.

61% of parent carers said no one contacted them to see how they were managing, or if they needed any additional support.

63% of parent carers said their connections to other people (loneliness) deteriorated.

Many parent carers have increased anxiety and lost confidence as a result of not leaving the home for long periods, and are keen to re-establish connections to other people, but many are still worried about the virus.

Less than 60% of families said they were contacted by their child's school/college during the Covid-19 pandemic.

Amaze arranged proactive check-in calls to the most vulnerable families which were very welcomed, but it would have been good to have (afforded to) do more of these, (earlier and more often.) We also delivered 'craft packs' to CYP who were not able to go out, and needed things to do, and 'goodie bags' to parent carers to remind them to look after themselves.

"Needed more people involved with us as isolated families. In the pandemic & [with] the vulnerability of my son, we did not speak or see anyone for weeks at a time. Three months was the longest period. No phone calls. No support. No help."

d) Home learning was not differentiated or tailored enough to meet the needs of CYP with SEND. Parent carers needed more help to support this. Parent carers are concerned their children have fallen 'further behind' and face bigger educational inequalities as a result.

Experiences of home learning differed, with some parents reporting that their child preferred this. However, lots of CYP with SEND found online learning a huge challenge and were unable, or refused, to participate, with parent carers reporting high levels of tension. Often the ability of a child to access learning was totally dependent on whether the parent was available and able to support them.

For those CYP where a place was allocated in school, and after the return to school for all pupils, the provision in school was very variable. Social distancing sometimes meant teaching assistants (TAs) could not always support a child effectively. Children would be expected to learn independently or given support by TAs who did not understand their needs. Some academic interventions could not be carried out due to support bubbles.

Where an online offer was not accessible for a child with SEND, they missed out on any connection with their peers and their school community, so became more isolated.

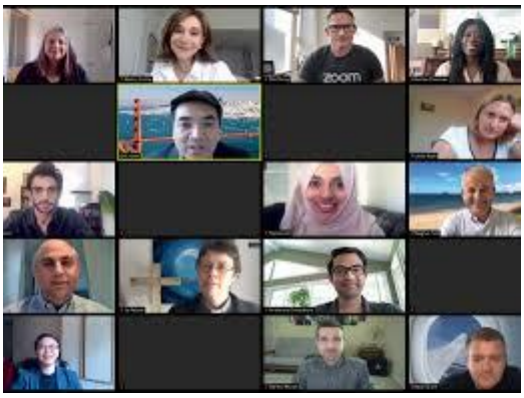
Parent carers have reported that in some cases it has been very difficult for CYP to go back to attending school face to face. Just under half of our respondents reported that their child's attendance and learning had got a lot worse since the pandemic. Schools/college did not always seek the views of CYP and parent carers on what additional support would be required for them to access learning throughout the pandemic, or indeed to 'catch up' as we moved out of it. Parent carers want to understand if schools, and other support services, can now provide extra support to help their child 'catch up' or close the attainment gaps which have got worse during the pandemic.

Siblings of CYP with SEND often missed out as a parent's attention was focused on the child with additional needs.

"School did not take into account my son's anxiety levels and change of routine, which meant he couldn't do the at-home learning they provided. More communication and listening to me would have helped."

"School said there was nothing they could provide us with for home learning as our daughter wouldn't engage virtually."

e) Some services were quicker to adapt and were more person-centred, flexible and understanding than others.



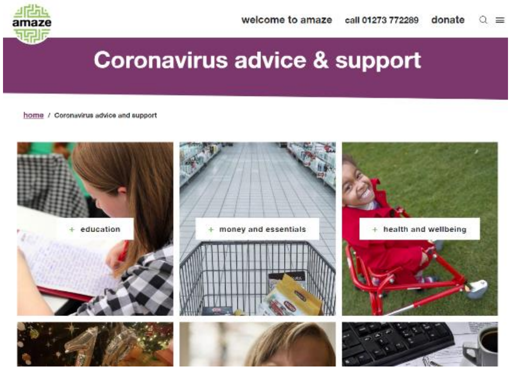
All services had to quickly adapt in order to continue providing appropriate support, and we know the huge efforts most went to, in what were hugely challenging circumstances. Most services developed an alternative, online offer, using software like Zoom/Teams.

Some families have liked online alternatives as they saved travel time and expense, but some have not wanted or been able to access these.

40% of parent carers and 38% of professionals felt that online services were not as good as face to face, in particular for certain kinds of (health) assessments

Amaze's proactive calls to the most vulnerable families on our case list, were highly appreciated, and parent carers wondered why more of these could not have been made, across a range of teams.

Parent carers turned to Amaze for local, SEND-specific interpretation of the ever-changing government guidance – via our FAQs (25%) and website (40%). Over 20,600 users have visited our Coronavirus information pages, with a further 5,330 viewing our advice on vaccination for CYP. But some parent carers do not want to get, or do not have access to, information online.



“Schools/therapists could have done Zoom sessions for parent carers to continue with the therapy.”

“Statutory services did not utilise their staff as effectively between them as they might have. There was a lot of fear which they allowed to dictate what they offered.”

f) Parent carers experienced confusion, frustration and anxiety about the Covid vaccine programme.

Parent carers told us they experienced a significant lag time from a national announcement before local areas had the operational guidelines or vaccine supplies to implement this. Also, carers found information about eligibility for vaccination unclear, insufficient or even discriminatory, for example information about vaccination for unpaid carers and whether carers of children were included. The Green Book guidance and public announcements and information about eligibility for vaccination did not always exactly tally, for example there was ambiguity about autism and about who would be seen as learning disabled. Despite Amaze working hard to lobby the Sussex Vaccination Board to ensure that all parent carers would be recognised under priority 6, many carers had exhausting and stressful experiences trying to establish if they or their CYP were eligible. In some cases, they this led to conflict with their GP and there is a risk that this will leave a legacy of mistrust.

“It was so hard to find out if our daughter was eligible. She has a life-limiting medical condition that causes uncontrolled epilepsy, but even her hospice team could not help with finding out when she would be eligible. It was a very stressful time.”

Carers spent time and energy trying to find reliable information; how to establish if they or their CYP was eligible; where and when vaccination would be available; would the necessary reasonable adjustments be possible; where to approach if their CYP had particularly complex needs, etc. Amaze tried to provide accurate and up to date information about the above, and our website viewing figures show this was well used.

Also, we found that parent carers were not clear to what extent vaccine services were prepared to offer reasonable adjustments (RAs) for disabled people of any age, for example how to ensure their CYP would not have to wait when they are unable to do so; how to establish that they would need to accompany a young adult; how to check that there would not be insurmountable sensory challenges (noise, lighting, crowds). Where reasonable adjustments were offered these tended to focus at first on physical access rather than sensory needs, high anxiety and distressed behaviour. Some carers

reported positive experiences, particularly as changes were made later in the programme, but initially there was a lack of flexibility and poor information about how to request adjustments when booking. It took a while for special sessions to be set up, booking teams to be given checklists about RAs etc - but it is clear from the survey responses what a difference these made.

Carers of CYP with particularly complex needs around vaccination had difficulty finding help to overcome these barriers, for example those with needle phobia. Some of these carers were caring for CYP at particularly high risk if they caught Covid, for example Down syndrome with additional medical issues, but past need for extensive medical intervention meant that highly tailored arrangements would be needed if vaccination was to be achievable. Some carers reported going to extraordinary lengths personally or relying on intervention by health staff who knew their CYP well to enable them to be successfully vaccinated.

"My daughter has severe needle phobia and PTSD after Cochlear Implant surgery. Trying to find support for her to have the vaccine was impossible."

"We had seven attempts at the first dose, which six of them ended up with no vaccine given as anxiety kicked in - was kicking out, shouting running away from mum, dad and nurses."

Carers' experiences around vaccination highlight that there is still insufficient understanding about learning disability and neurodevelopmental conditions such as autism within some NHS services outside those that specialise in these areas. Carers reported individual kindness but also barriers to vaccination take up due to lack of this knowledge in the workforce. Some carers in the group who declined vaccination made this decision not because of doubts about vaccination but because they did not believe the vaccine programme could offer an arrangement to vaccinate their child without excessive distress.

The roll out of vaccination to CYP at high risk relied on GP patient records and this revealed gaps in the information GP services hold about CYP with SEND. Children with medical conditions met by specialist paediatric services were successfully identified, but children with learning disabilities and developmental conditions are primarily seen by child development centres and community paediatrics and their needs not so clearly known to GP services. For CYP with learning disabilities there was reliance on Learning Disability Registers but these do not include younger children and are incomplete. Some carers in the group who declined vaccination made this decision because they were unable to get information to satisfy their concerns about the risk versus benefit equation for their individual CYP in the light of their specific health and medication profile.

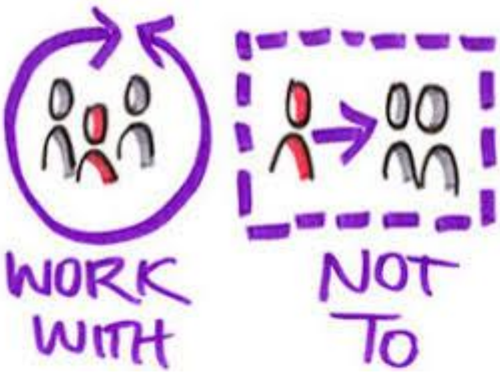
Carers' experiences around seeking vaccination for themselves highlighted that parent carers are not always recognised as carers by services. Some parent carers were told by GP practices that they only identified those caring for adults when flagging carers in their records. Some parent carers felt let down and their caring role unappreciated by the health system as a whole or by specific components e.g. their GP practice, whilst understanding the exceptional pressures facing the NHS and GPs during the pandemic. Vaccination arrangements did not take into account the additional pressures faced by carers, for example needing to find care for their disabled CYP in order to attend vaccination.

g) Understandably, services were in crisis mode, but more should have paused to ask parent carers to identify needs and co-produce solutions

Very few respondents said they had made changes to their service offer in coproduction with CYP with SEND and their families, citing lack of time as the main reason.

As part of this research, parent carers have offered a huge range of ideas and suggestions on what services could have done better, illustrating how useful seeking and using their input is.

In addition to providing direct services, Amaze spends time working collaboratively with other services and commissioners, to influence policy and practice. We work closely with the parent carers' forums across Sussex - the Brighton and Hove Parent and Carers Council (PaCC), East Sussex Parent Carers Forum (ESPCF) and West Sussex Parent Carer Forum (WSPCF) with whom we highlighted unmet needs and concerns from the SEND community, and supported their coproduction of services.



We quickly identified that accessing the outdoors, was problematic for families with CYP with SEND, especially those without a garden. They needed greater flexibility to go outside more than half an hour per day. So, in coproduction with parents, we developed a template letter that we shared with Sussex Police, that families could carry on them to give them reassurance that they were not going to be arrested. Accessing supermarket slots was another key area of stress, so we produced another letter, which allowed families with a Compass Card, priority access to supermarket shopping slots. In doing this piece of work we learnt that there needs to be some work around ensuring that Carers/Compass Cards are more widely recognised at times like this, and immediate concessions/priority given to the holders.

"During the lockdowns, I think services were in a 'heads down' situation dealing with immediate risks, adjusting to working from home, own service pressures and we lost the opportunities for more joint working"

4. Conclusions. Synthesis

This report clearly highlights the increasing inequality and additional, multi-faceted challenges and barriers that parent carers and CYP with SEND have faced over the past two years. Parent carers have generally felt less supported and more isolated, and CYP with SEND have faced longer waiting times, reduced services and increased anxiety.

For many CYP with SEND, as well as their carers, schools and the services that support them – Covid-19 is still very much a 'live problem', and many of us are emotionally and physically exhausted from firefighting the many fall outs from the last two years.

The pandemic has taught us that we can all be more flexible in how we deliver our work; there are other ways of working that can be of benefit to CYP with SEND, and their families. Wherever possible, we should take this as an opportunity to change the shape of provision, and tailor it to suit each individual's needs, whether this is smaller class sizes, how we offer vaccinations to CYP with additional needs, offer a hybrid working pattern or more flexibility around accessing appointments.

Children and young people with SEND and their parent carers really are the experts in their own care, and we all need to commit to working ever more in co-production.

5. Conclusions. Next steps

Our recommendations are made up of suggestions from parent carers and professionals' feedback, presented under each key theme, as follows:

a) Parent carers are exhausted from the added pressures of the last two years. Not enough respite was available.

- Partners need to work together to increase parent carer identification, registration on GP and local authority Carers' Registers.
- Local authorities and clinical commissioning groups need to review how assessments of parent carers' (holistic) needs are carried out, evaluate how effective these are, and what they tell us about additional support needed.
- In future, we should ensure personal assistants and short breaks providers are classified as essential/emergency services, that need to remain working/open at all times.
- Social care staff need to encourage parent carers to think how they could use direct payments more creatively, in times of emergency, without decisions needing to go back to a panel.
- Services should clarify what support is available for managing increasing behaviour that challenges at home.

b) High levels of stress and anxiety led to poorer health and wellbeing:

- All schools to focus on pupil wellbeing above academic pressures.
- We need to ensure educational needs are met in schools, since this supports children's emotional wellbeing as well as their education.
- As a sector, we need to continue to lobby for greater investment for, and commissioning/monitoring of, mental health services – in particularly CAMHS – and there needs to be a systemic shift to offer more preventative wellbeing support.
- CYP on neurodevelopmental pathways and their parent carers need easier access to mental health and wellbeing support, and wider family support, both pre and post-diagnosis.
- We should improve our knowledge and research base around links between autistic girls, masking and links to mental health presentations.
- CAMHS delivery needs to be more person-centred, and less clinic-oriented.
- Counselling needs to be made more easily available and adapted for CYP with SEND, and parent carers who report high levels of anxiety.
- All parent carers should be encouraged to join their GP's Carers' Register – and carers should be offered an annual health check-up, including the offer of counselling or therapeutic treatments - if they present with a decline in their mental health and wellbeing.
- We need to develop more support and counselling options for sibling carers.
- Specifically, for Amaze, we need to:
    - Review our provision of services to young people/parents who are experiencing poor metal health and seek new funding partnerships to provide 'early help' support

  - Fundraise to create a better counselling offer for parents/young people – as waiting lists too long and people are going without. [or via a partnership with an established provider]
  - To build the 5-ways to wellbeing into everything we do
  - Continue to improve support for staff wellbeing – as the needs of families have increased in complexity and difficulty
  - Seek more investment to provide more capacity on our Advice Line to respond to the more challenging calls we are receiving

c) Parent carers became more <u>isolated</u>, as many were shielding clinically vulnerable children for much longer. There was not enough proactive support or outreach to help, or recognition of the added challenges they faced with disabled children at home for longer.

- Need to increase opportunities for CYP, and parent carers, to meet up socially, in their local community, to feel more connected, and less isolated. Include those living in the most geographically isolated/rural areas.
- Do not assume all parent carers can or want to, engage online. Offer face-to-face support alternatives for those who prefer these, in their local community.
- Services to work together better to identify, then contact and offer (person-centred) support to, the most vulnerable families, sharing capacity to avoid duplication of effort.
- Clarify how parent carers want to access information and be contacted, so they feel more connected and empowered. Always store 'communication preferences' and keep these up to date.
- Offer more activities that parent carers can access with their family.
- Offer moderated peer-support groups on WhatsApp, putting in place group chat rules around conduct so people feel safe to share how they are feeling.

d) Home learning was not differentiated or tailored enough to meet the needs of CYP with SEND. Parent carers needed more help to support this. Parent carers are concerned their children have fallen 'further behind' and face bigger educational inequalities as a result.

- Clearly the best solution is to ensure schools remain open to all children wherever possible, but especially prioritise CYP with SEND (not just those with an education, health and care plan).
- If CYP with SEND have to learn from home, ensure the appropriate equipment is available and that they are provided with differentiated learning resources, regularly checking in with parent carers if they are able to access these.
- We need to identify other tailored ways of providing remote learning if CYP are unable to access the online offer, for example Zoom sessions with staff, set tasks that they can access without adult support.
- Schools need to consider the inequality of learning experiences that CYP with SEND have had and develop and communicate a 'catch-up' plan.
- Local authorities and schools to develop a better understanding of CYP with SEND who have not returned to school/college and focus efforts on getting them back into education with the appropriate staffing to support them.

e) Some services were quicker to adapt and were more person-centred, flexible and understanding than others.

- All services need to continue a hybrid offering to CYP with SEND and their parent carers that is person-centred according to their preferences.
- Statutory services, which often provide for the most vulnerable, must build in the ability to be flexible and quickly adapt to the needs of those who rely on them.
- We should always consider the most vulnerable people, and what extra help they might need to be heard, reached and supported.
- Therapy services should consider what therapy interventions can continue online (one-to-one sessions, small groups, Q&As with therapists or webinars for parents).
- There needs to be a clear offer of what counselling (and other support) is available for parent carers, and how to access this.
- We need to ensure carers can be quickly identified and look at whether existing schemes like the local Carers/Compass Cards can be more widely used as identification to access range of concessions/priority services.
- Partners need to work together quickly to develop accurate, local SEND-specific information in the event of a crisis like the pandemic. It should be published in a range of accessible formats, by a trusted, impartial provider.
- All services should communicate updates/changes using a range of methods; they should not just be on Facebook or websites; they need to also write/text/call.
- Specifically for Amaze:
    - We need to consider how to better manage very high workloads and the impact these are having on our staff's wellbeing. Seek increased funding to mirror the increases in demand and complexity of needs across all our services.
    - We need to continue to have a hybrid working model for Amaze staff - to ensure they are connected and share learning with their colleagues, whilst retaining the benefits of some home working.

h) Parent carers experienced confusion, frustration and anxiety about the Covid vaccine programme.

- Learning from this programme should be captured and applied to any future mass vaccination or public health programme, with planning from the start to offer and publicise arrangements for reasonable adjustments and special arrangements. There should be national guidance around dealing with needle phobia and a flexible and creative approach for the most complex and vulnerable individuals. Issues such as the use of sedation in exceptional cases should be resolved.
- More care given to how health messages are communicated when they impact groups who already face stress and challenges. Better partnerships with national and local carer's organisations to check information is carer-friendly and to disseminate targeted information.
- Learning disability and neurodevelopmental conditions needs to be a priority for continued training across the NHS workforce, in line with the Oliver McGowan Mandatory Training programme. It is important to recognise the knowledge of carers about the needs of those they care for in this training and the need for NHS staff to work well with carers to best meet the health needs of children and adults with learning disability and autism.

"Being able to discuss in detail the reasons my son was being offered the vaccine prior to him receiving it with the doctor running the clinic was really helpful and allowed me to be more confident in my decision to get him vaccinated."

- Green Book wording needs to be unambiguous. GPs and local vaccination programmes need to get information promptly following national announcements.

- Further promotion of Learning Disability Registers with GPs and the community to encourage more consistent registration. Further clarify guidance about who should be on these registers and from what age. Vaccination or other mass public health programmes need to make sure primary health care staff are prepared to respond to specific queries about the safety and risk for CYP who have SEND including long term health conditions.
- Need further work on carer awareness and carer recognition across the health workforce and particularly with GP services. Support for carer registration with carer organisations, including parent carers of under 18s.

f) Understandably, services were in crisis mode, but more should have paused to ask parent carers to identify needs and co-produce solutions

- All services need to acknowledge the significant value and vital role of listening to the communities we are trying to serve, then working in co-production with them – ensuring time is found for this.
- Co-production needs to include a broad range of participants – from CYP with SEND, parents and carers and disabled people, from diverse groups.
- All services need to have a plan for how parent carers will be communicated with.
- After any engagement activity, services need to commit to feeding back how people's input has been used to affect change.
- All service managers and commissioners to read the full findings of this report and consider how they can plan to consult and communicate more specifically with their community of SEND families.

Amaze plans to incorporate this learning, and recommendations we have influence over, into our future work, and we will share these key lessons and themes with local authority, schools, health services, and other community and voluntary sector partners and invite reflection.

We will ask that our recommendations are incorporated into relevant places in local SEND Strategies and commissioning plans, and we will share the findings with the partners we work with nationally. We hope national decision makers will take on board the wider suggestions for greater investment, in particular for mental health services, and about prioritising all SEN-support children and their parent carers, if (heaven-forbid) there was ever another national lockdown.

We also commit to sharing this report on our website and make sure parents and professionals who contributed, receive a copy.

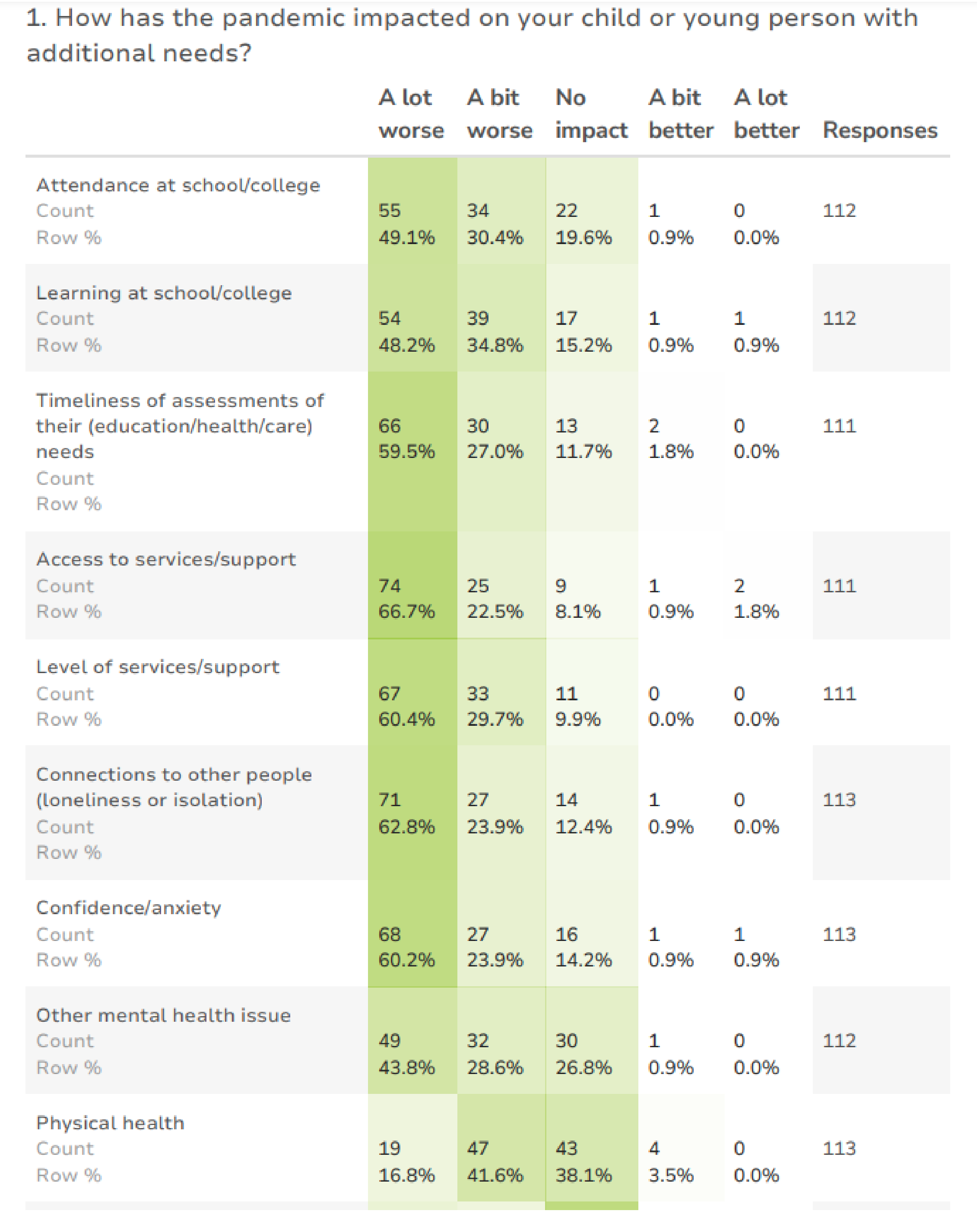
Our longer report including all the survey findings and graphs in full, can be found below.

APPENDICIES

FULL SET OF RESPONSES AND FINDINGS TO THE AMAZE THINK CARER NHS ENGLAND RAPID EVALUATION

General findings about the impact of the pandemic

We asked both parent carers and professionals working with them, how the pandemic had impacted on children and young people with SEND and their parent carers. The findings are below:



1. How has the pandemic impacted on your child or young person with additional needs?

	A lot worse	A bit worse	No impact	A bit better	A lot better	Responses
Attendance at school/college Count Row %	55 49.1%	34 30.4%	22 19.6%	1 0.9%	0 0.0%	112
Learning at school/college Count Row %	54 48.2%	39 34.8%	17 15.2%	1 0.9%	1 0.9%	112
Timeliness of assessments of their (education/health/care) needs Count Row %	66 59.5%	30 27.0%	13 11.7%	2 1.8%	0 0.0%	111
Access to services/support Count Row %	74 66.7%	25 22.5%	9 8.1%	1 0.9%	2 1.8%	111
Level of services/support Count Row %	67 60.4%	33 29.7%	11 9.9%	0 0.0%	0 0.0%	111
Connections to other people (loneliness or isolation) Count Row %	71 62.8%	27 23.9%	14 12.4%	1 0.9%	0 0.0%	113
Confidence/anxiety Count Row %	68 60.2%	27 23.9%	16 14.2%	1 0.9%	1 0.9%	113
Other mental health issue Count Row %	49 43.8%	32 28.6%	30 26.8%	1 0.9%	0 0.0%	112
Physical health Count Row %	19 16.8%	47 41.6%	43 38.1%	4 3.5%	0 0.0%	113

Overall, the pandemic has made things worse for the majority of CYP with additional needs across all the areas we explored:

- 89% said both their child's 'access to services and support' and 'level of service/support' had got worse, with 67% and 60% respectively saying it had got a lot worse.
- 63% said they felt their child's connections to others (loneliness) had got a lot worse
- 60% and 44% respectively said their child's 'confidence' and 'other mental health issue' had got much worse
- 49% said attendance at school/college had got a lot worse, with 48% saying learning had been badly impacted.
- Although 42% reported their child's physical health to be a bit worse, fewer parents felt it had been made a lot worse (17%) when compared to the other indicators.

It is also worth noting other ways in which the pandemic impacted on CYP with SEND, and those mentioned by parent carers include the negative effect of being on a computer/tablet all day every day to access home learning, mask wearing and the confusion for CYP as to the rules around mask wearing changed and medication reviews not taking place.

Direct quotes from parent carers:

"School did not take into account my son's anxiety levels and change of routine, which meant he couldn't do the at home learning they provided. More communication and listening to me would have helped."

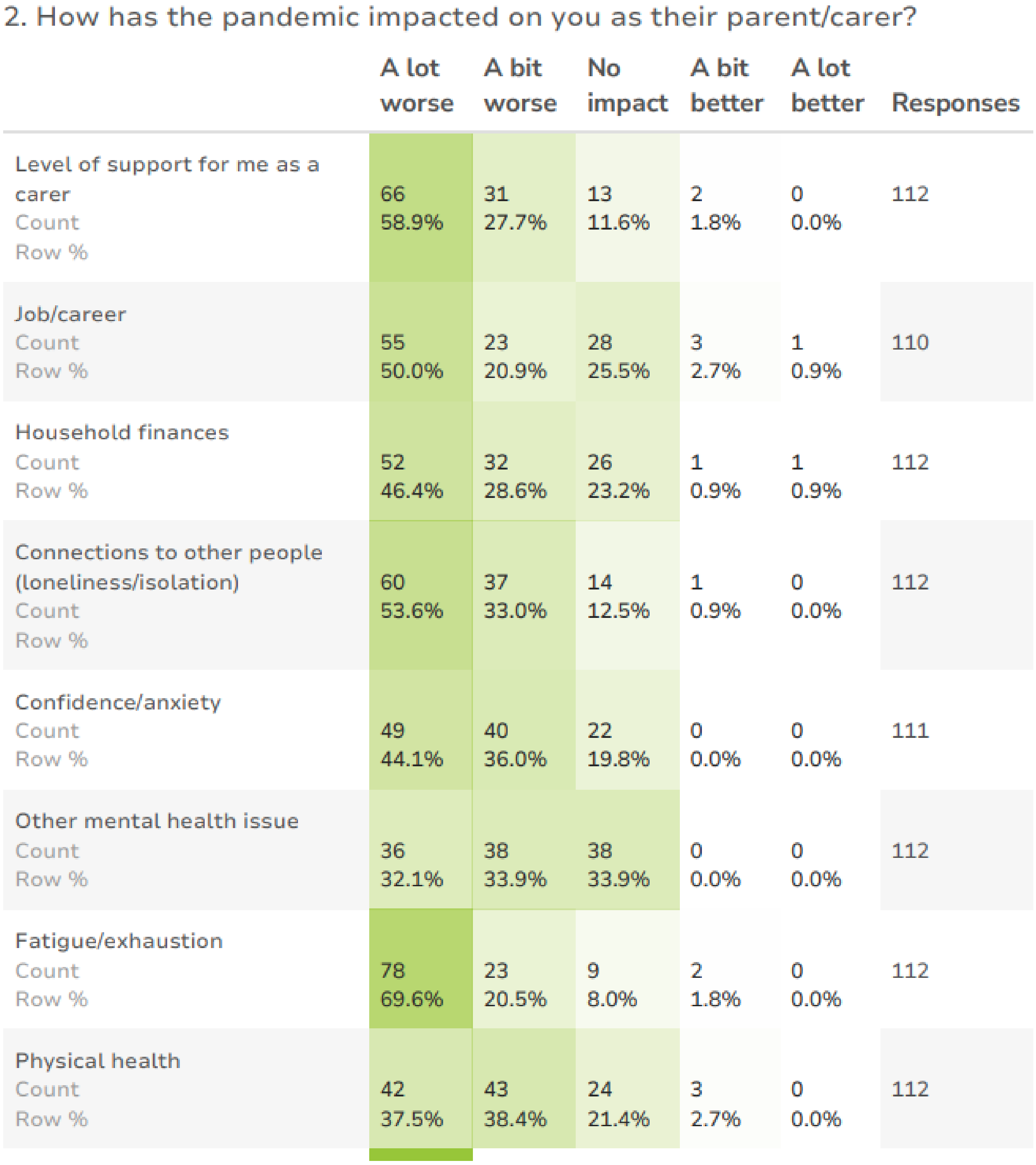
"Family mental health went down, son became more closed off, no access to mental health support through CAMHS"

Direct quotes from professionals:

"Huge amount more could have been done, to provide more mental health support to children with ASC and SEN and to proactively support access to education during and after pandemic"

"There were very difficult periods when the usual services that families depended on were unavailable"

We then asked how the pandemic had impacted on parent carers specifically. The findings are below:



2. How has the pandemic impacted on you as their parent/carer?

	A lot worse	A bit worse	No impact	A bit better	A lot better	Responses
Level of support for me as a carer Count Row %	66 58.9%	31 27.7%	13 11.6%	2 1.8%	0 0.0%	112
Job/career Count Row %	55 50.0%	23 20.9%	28 25.5%	3 2.7%	1 0.9%	110
Household finances Count Row %	52 46.4%	32 28.6%	26 23.2%	1 0.9%	1 0.9%	112
Connections to other people (loneliness/isolation) Count Row %	60 53.6%	37 33.0%	14 12.5%	1 0.9%	0 0.0%	112
Confidence/anxiety Count Row %	49 44.1%	40 36.0%	22 19.8%	0 0.0%	0 0.0%	111
Other mental health issue Count Row %	36 32.1%	38 33.9%	38 33.9%	0 0.0%	0 0.0%	112
Fatigue/exhaustion Count Row %	78 69.6%	23 20.5%	9 8.0%	2 1.8%	0 0.0%	112
Physical health Count Row %	42 37.5%	43 38.4%	24 21.4%	3 2.7%	0 0.0%	112

The stand out area for how the pandemic has impacted on parent carers is fatigue/exhaustion, with 70% saying it is a lot worse.

- 59% felt the level of support for carers was made much worse
- 50% of parent carers reported their job/career was ‘a lot worse’ – with many saying they had to work fewer hours, take furlough or give up work in order to care for their child(ren)
- 54% said they felt their connections to others (loneliness) had got a lot worse
- 44% and 32% respectively said their ‘confidence’ and ‘other mental health issue’ had got much worse – increasing to 80% and 66% respectively who reported it worsening
- 75% said their physical health had worsened

Direct quotes from parent carers:

"I didn't get any support nor did my child. I feel it's easier for them to ignore you and hope you don't ask for help."

"Online counselling: everything was happening on Zoom; no alternative support for my child during a time when he lost his dad and I was feeling completely burned out."

"Shopping at supermarkets: it was great to have the letter that enabled families to not have to stand in a queue for hours."

Direct quotes from professionals:

"The government should put more funding into all services but especially mental health services for parents and young people & children."

"Given parents a break from their caring role but this would have broken government guidance. Not closed SEND schools during lockdown as they are an essential service."

Lots of parent carers have reported feeling anxious about their child's loss of time in school or college during the pandemic. We asked if their child had been able to return to education since:

- 55% reported they had (at pre-pandemic levels),
- 25% reported attending but at lower levels than before
- Interestingly 4% reported better attendance than prior to the pandemic
- 4% reported they are still shielding at home
- 4% have decided that the setting they were in is no longer able to meet the CYP's needs so are home educating

It has been acknowledged that a 'catch up programme' would help with the potential educational attainment gap, but with only 55% reporting their child attending at a pre-pandemic rate, it is hard to see how many CYP would be able to access any form of catch up.

It is also important to note that many schools/colleges are still having to part-close some classes, due to so many staff being absent with Covid, or Covid related issues.

Direct quotes from parent carers:

"Daughter has developed agoraphobia since the pandemic began."

"Started a college course in September but left end of November as couldn't cope."

Direct quotes from professionals:

"The pandemic is still current, it has not passed. There are still staff shortages across all settings. There will need to be a period of time post pandemic when services can reflect, as we are still dealing with issues in a fire fighting way and staff are emotionally and physically exhausted".

"Support to children to continue accessing education/school attendance should have been prioritised."

Findings about Amaze's Response and Services

In our internal review, our management team felt we had reacted swiftly to the changing guidance and needs of families throughout the two-years of the pandemic. We quickly set all our staff up to work from home, then worked out a way to reshape our services so we could continue to run everything remotely.

A lot of our information, advice and support was already provided virtually – via the phone, text, email or web-based resources – so we were well set up in this. But we acknowledge that staff shortages at times throughout the pandemic (as many of our staff were also attempting to home school their children, or were shielding their CYP with SEND) meant that our response times, or waiting lists were longer than we would have liked.

Also, our Face to Face and Amazing Futures individual befriending and group peer support had to completely change their model - away from face-to-face groups, meeting inside, to groups meeting on line. For some this worked better, with parent carers in more geographically remote parts liking that they could attend things without having to travel, and citing they were able to access more services than previously. We were also able to make better befriender/befriendee matches – based on their personal experiences and not having to consider geographical proximity to each other.

However, we know some people didn't like to appear on screen eg at Triple P Parenting training courses, so they may have chosen to not attend. An indirect benefit of training carers together in a group in person, is the informal bonding and creation of a peer support network which naturally develops over a 6-8 week course. This proved hard to replicate on Zoom.

Some young people were happy to attend alternative Zoom activities initially and our staff worked hard to keep these 'fresh' and offer fun things the young people said they would like eg 'bring your pet', cookery and disco sessions. However, attendance numbers soon tailed off and YP told us they wanted to revert to meeting face to face. So as soon as the guidance allowed, we arranged 1:1 walks, and spaced-out activities in local parks eg yoga.

After about 4 weeks we recognised that we had not heard from some of our most vulnerable families, so we shifted a member of staff to spend a week making proactive, check-in calls with them. Many parent carers said we were the first people to make contact with them, and they were incredibly grateful that we had taken the time to do this. Often the calls led to a parent identifying a range of things that were not going well for them or their child, which we could help with.

As well as our own direct services, we worked hard to influence our partners working across education, health and other SEND teams. In the first few months, our CEO attended daily, then every two days, meetings with the Lead for SEND at Brighton and Hove City Council – feeding in what families were telling us on the ground, and offering support or other solutions. We quickly identified that accessing the outdoors, was problematic for families with CYP with SEND, especially those without a garden. They needed greater flexibility to go outside more than half an hour per day. So in coproduction with parents, we developed a template letter that we shared with Sussex Police, that families could carry on them to give them reassurance that they were not going to be arrested.

Accessing supermarket slots was another key area of stress, so we quickly produced a letter, which allowed families with a Compass Card, priority access to supermarket shopping slots. In doing this piece of work we learnt that there needs to be some work around ensuring that Carers/Compass Cards are more widely recognised at times like this, and immediate concessions/priority given to the holders.

During the lockdowns, accessing leisure venues was impossible so the vast majority of Compass Card [1]offers were unavailable. However, we worked with a number of organisations to ensure online activities were accessible to card holders, including things like discos, computer coding, dance, music and theatre performances. We also worked with local taxi firms and food outlets to ensure Compass Card holders were prioritised and received discounts.

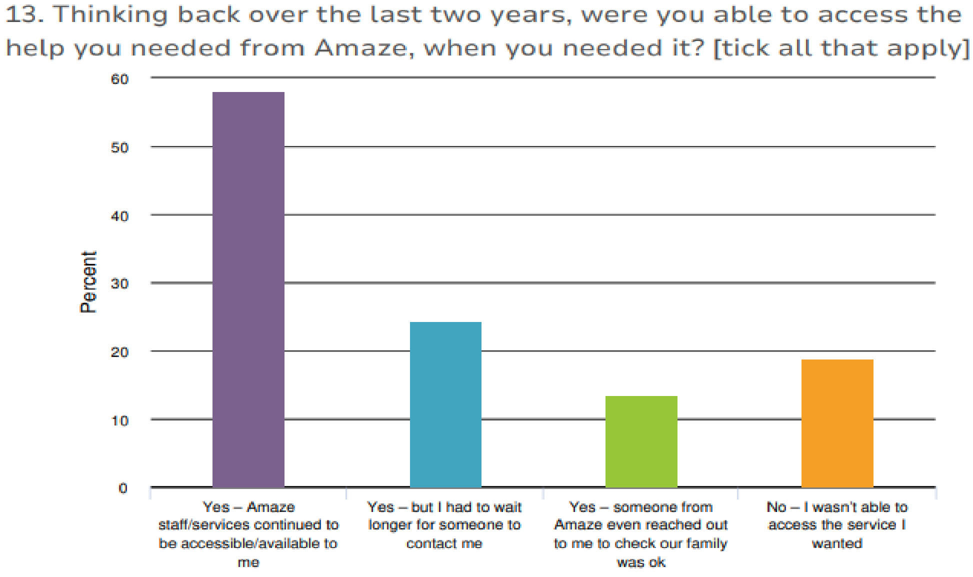
We worked closely with Brighton & Hove Libraries to distribute over 100 codes giving free access to the ‘Hopster’ app for one year. The app is packed with fun and educational games, as well as having a SEND area with guidance for parent carers on how to get the best out of the app.

Amaze was commissioned by East Sussex County Council and Brighton and Hove City Council to give out 343 Covid-19 Winter and Summer Grants to the most vulnerable families we were seeing, total value £40,150. We gave these as 1 or 2, £50 cash payments per child direct into their bank accounts to help them pay for food or fuel bills. Families appreciated having the cash to give them choice and control over where to spend this, rather than vouchers for specific shops which they say might not always be suitable.

We undertook other wellbeing initiatives like delivering ‘craft packs’ to YP who were not able to go out, and needed things to do, and ‘goodie bags’ to parent carers to remind them to look after themselves.

While we think we did a good job, we wanted to look further at whether, in hindsight, we focused on developing the right services that parent carers most needed at key points in the pandemic, or what more we could have done differently. We also wanted to find out if our influencing/lobbying activity was impactful and delivered results on the ground for families.

We asked parents if they had been able to access Amaze services during the pandemic, when they needed them.


13. Thinking back over the last two years, were you able to access the help you needed from Amaze, when you needed it? [tick all that apply]

- Nearly 60% of parent carers said they were able to access help from Amaze.

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[1] The Compass Card is a leisure discount card for children and young people aged between 0 and 25 years on the Disability Register in Brighton & Hove. The Compass Card provides hundreds of discounts to leisure opportunities across the city, the vast majority of which had to close at the start of the Pandemic.

- 24% felt they had to wait longer to access our services, which is due to staff sickness, and offering furlough to some of our parent carer staff
- 13% reported that Amaze proactively contacted them to 'check in' with them to see how they were doing and if there was anything Amaze could do to support.
- But disappointingly 19% said they were unable to access our services

When exploring why this might be, the majority of respondents told us that there was not an online option that they were aware of. This could have been as our messages were not reaching people, or that there was a service which was unable to go online e.g. Compass Card.

Direct quotes from parent carers:

"I didn't know about Amaze until the end of the pandemic."

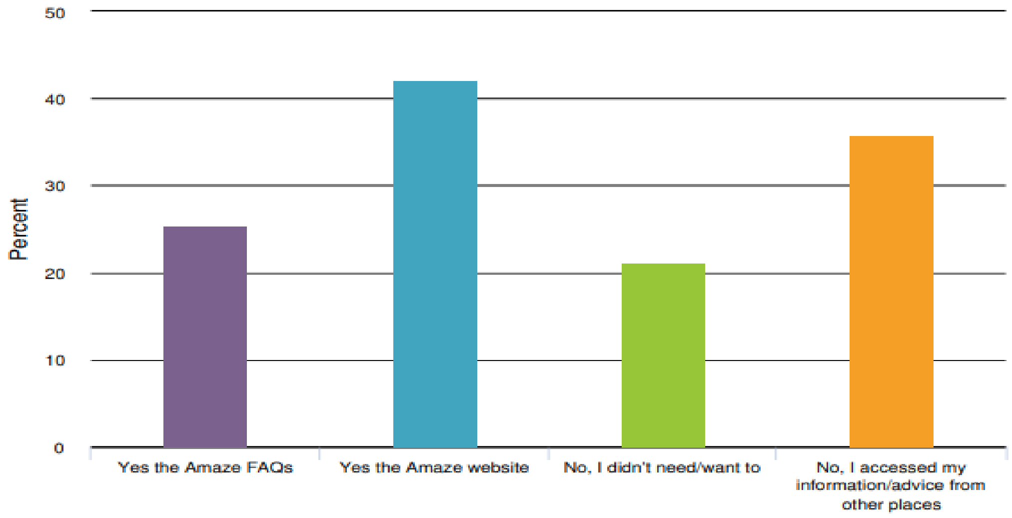
"I didn't know what was available."

As a take away from this question it will be important to look at the ways in which we communicate our services to families. At the moment we rely heavily on social media and mail outs/ targeted emails to families on the Disability Register.

Early on, we knew that many parent carers were struggling to understand the rapidly changing, and complex guidance coming out from the government, so we quickly developed a range of parent carer specific Covid-19 FAQs, before developing a Covid-19 section on the Amaze website.

We asked parent carers and professionals if they had made use of these resources.

12. Amaze tried to respond quickly to the CV19 crisis, developing a range of parent carer specific Covid-19 Frequently Asked Questions (FAQs) – translating often very complicated government guidance, into more readable information, specific to the needs of our local community. We then built a new CV19 section on our website see here. Did you use either of these resources?



Amaze responded quickly to the CV19 crisis, developing a range of parent carer specific Covid-19 FAQs and web pages – translating often very complicated government guidance, into more readable information, specific to the needs of our local community - https://amazesussex.org.uk/coronavirus-advice/. These pages had over 20,000 page views during the year and helped us attract over 52,000 new users to our website. From those completing the survey, over 40% had used the Amaze website and a quarter used the Amaze Covid-19 Frequently Asked Questions (FAQs) at this difficult time.

Over 20% of parent carers felt they did not need or want this information and around 35% accessed this information from other places.

Professionals tell us they also make good use of our online resources – with half using the Amaze website, and over a quarter accessing our FAQs. Around 15% of the professionals asked did not need or want to access this information and around 35% accessed it elsewhere.

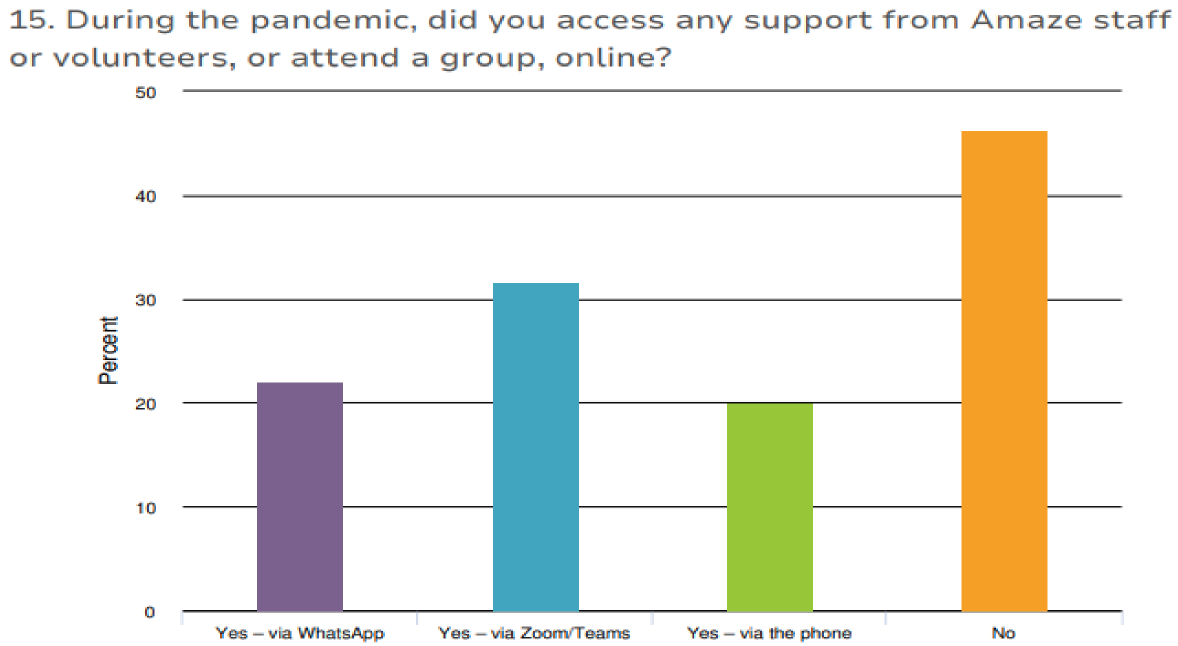
This confirms how useful the SEND specific Covid-19 information was to many parent carers and professionals. As a follow up we would like to find out more about where else people choose to access information as we could look to collaborate with other providers, so we do not duplicate effort, if there is good content developed elsewhere.

Direct quotes from parent carers:

"Thank you so, so much Amaze, for all you've done to support us. Without your guidance I would not have come through this the way I have and been able to care for my son like we did. Most certainly he'd probably have gone in to a facility and things would have been much worse but instead I could access support and tools to do it at home, knowing I could get through this difficult time."

"If you don't access the internet to find them you don't know. Perhaps more information to be relayed other ways - text message or post or email to say "you could be entitled to help" etc."

Parent carers were asked if they received any support from Amaze online, and this is what they told us:



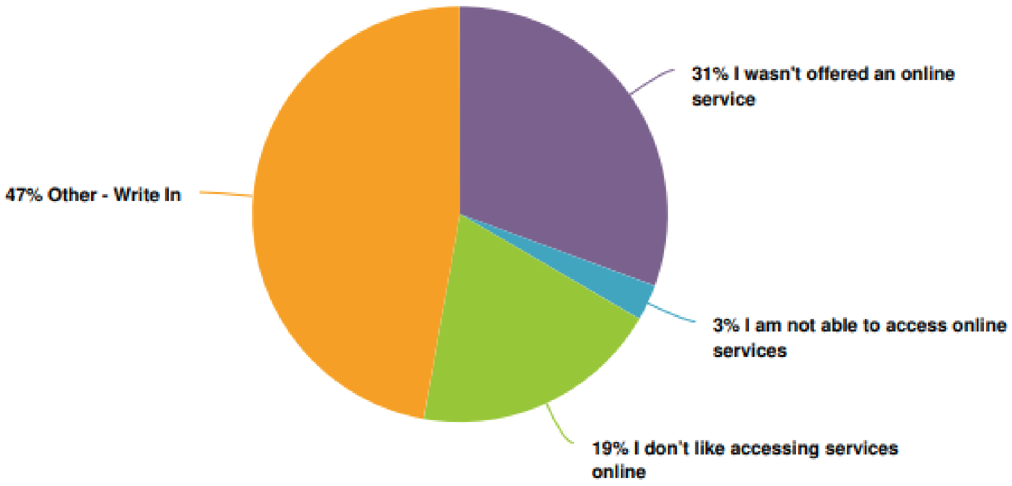
46% did not access any service remotely

31% accessed a service via Teams/Zoom - for those families who are comfortable online this meant they could attend workshops or events that perhaps would not be possible otherwise.

21% accessed support via WhatsApp. - Prior to the Pandemic we were not utilizing WhatsApp but it has become a great tool to reach our Face 2 Face families. Not only does it work well to keep parent carers connected with the work Amaze are doing, the groups also provide a way to facilitate peer to peer support.

Those that didn't, told us:

16. Why not?



- 31% said this was because they were not offered an online service. A learning is that we need to be more explicit with our communications around online services. We promote our online workshops and groups in a variety of ways including Eventbrite, social media, WhatsApp groups, our website and Amaze newsletter, but we need to look to see if there are other (offline) ways we can make parent carers aware of online support eg text, letters.
- 3% couldn't access online services
- 19% said they didn't like accessing online services. Throughout the Pandemic we have been aware that not everybody is comfortable online, although it is worth noting that for some parent carers it is an easier, more accessible way to access support.

We acknowledge that not all parent carers have access to the internet and it is important that we find ways to reach those families who cannot access our information online.

We also need to look at other ways of communicating, for example using different social media platforms for young people, e.g. TikTok.

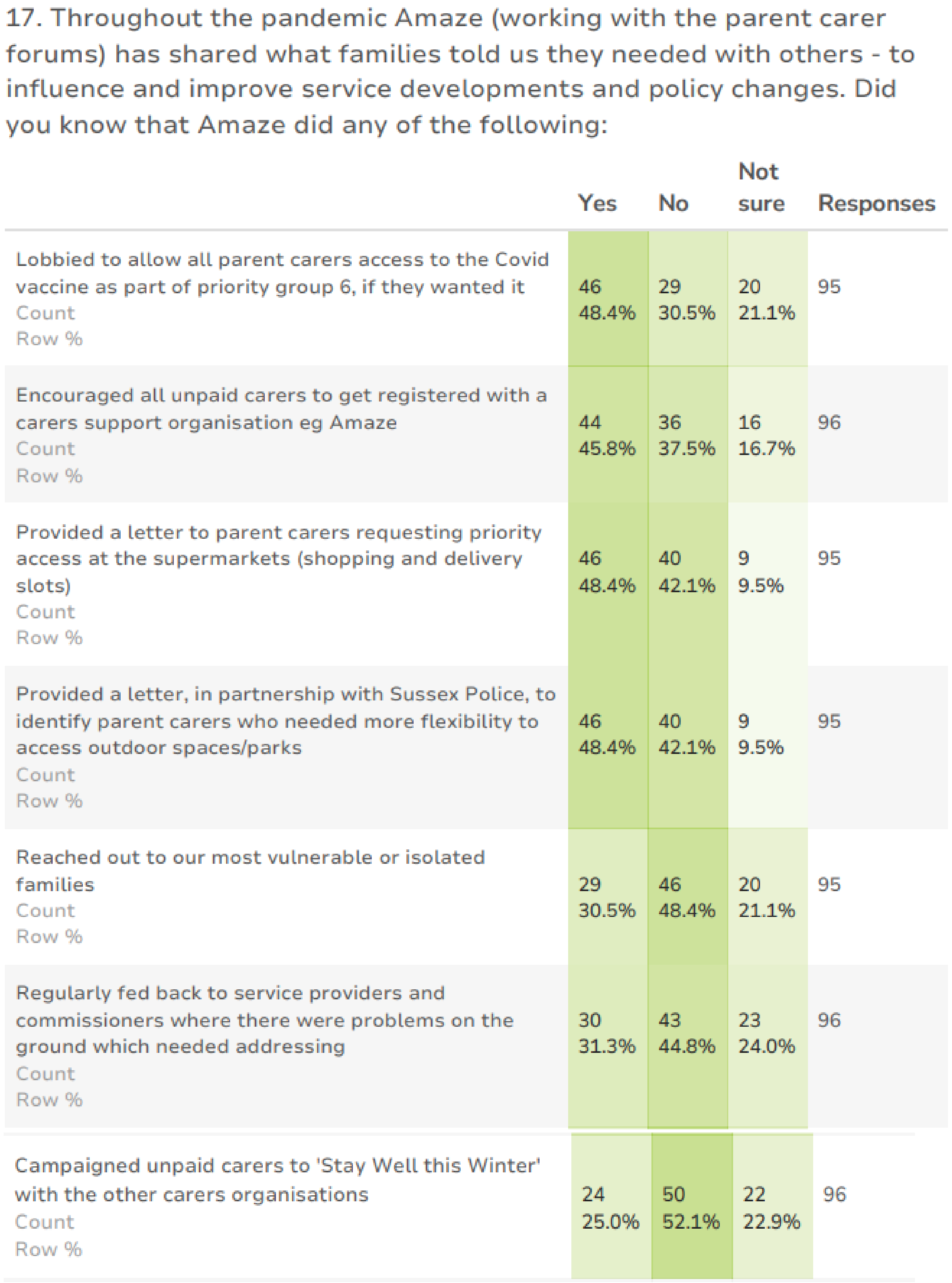
Direct quotes from parent carers when asked what we could have done better when offering support online:

"Unable to access anything online while caring 24/7 working and home schooling."

"I wasn't aware of online services."

In addition to providing direct services, Amaze spends time working collaboratively with other services and commissioners, to influence policy and practice. We work closely with the parent carers' forums across Sussex - the Brighton and Hove Parent and Carers Council (PaCC), East Sussex Parent Carers Forum (ESPCF) and West Sussex Parent Carer Forum (WSPCF) with whom we highlighted unmet needs and concerns from the SEND community, and supported their coproduction of services.

We asked parent carers if they knew we had helped influence the following:



17. Throughout the pandemic Amaze (working with the parent carer forums) has shared what families told us they needed with others - to influence and improve service developments and policy changes. Did you know that Amaze did any of the following:

	Yes	No	Not sure	Responses
Lobbied to allow all parent carers access to the Covid vaccine as part of priority group 6, if they wanted it Count Row %	46 48.4%	29 30.5%	20 21.1%	95
Encouraged all unpaid carers to get registered with a carers support organisation eg Amaze Count Row %	44 45.8%	36 37.5%	16 16.7%	96
Provided a letter to parent carers requesting priority access at the supermarkets (shopping and delivery slots) Count Row %	46 48.4%	40 42.1%	9 9.5%	95
Provided a letter, in partnership with Sussex Police, to identify parent carers who needed more flexibility to access outdoor spaces/parks Count Row %	46 48.4%	40 42.1%	9 9.5%	95
Reached out to our most vulnerable or isolated families Count Row %	29 30.5%	46 48.4%	20 21.1%	95
Regularly fed back to service providers and commissioners where there were problems on the ground which needed addressing Count Row %	30 31.3%	43 44.8%	23 24.0%	96
Campaigned unpaid carers to 'Stay Well this Winter' with the other carers organisations Count Row %	24 25.0%	50 52.1%	22 22.9%	96

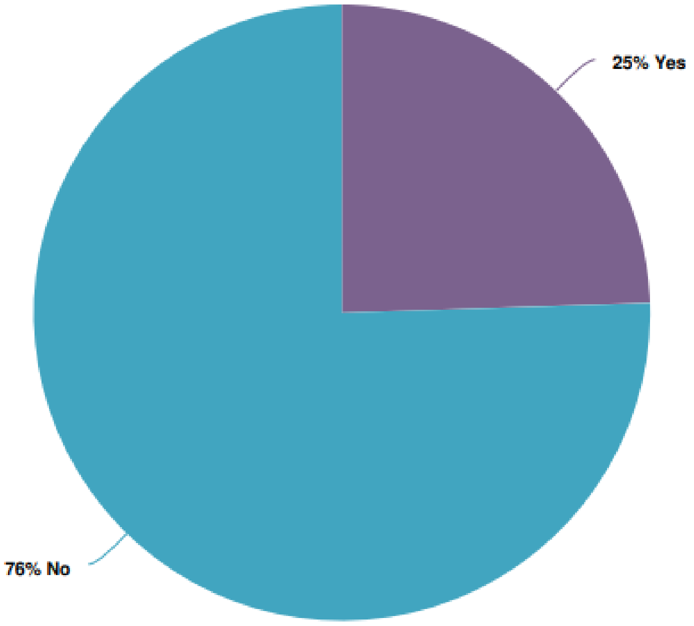
Nearly half of respondents knew Amaze had lobbied to ensure parent carers were able to access the Covid-19 vaccination under priority group 6, and knew we had provided letters to support their priority access to supermarket slots and to give them more flexibility to access the outdoors.

Fewer parents knew we had done other things like reaching out to the most vulnerable families, and having regular meetings with commissioners.

As an organisation we need to think about how we better promote this important area of our work so that parent carers understand Amaze provides more than just direct support.

We asked parents and professionals how Amaze could have improved our support to families during the pandemic:

18. Thinking back, is there anything else that you think Amaze could have done to better support you or your family during the pandemic – whether this is a service we could have provided, or something we could have tried to influence?



It is hugely reassuring to see that 76% of parent carers, and 87% of professionals, did not think Amaze could have done any more to support them during the pandemic. However, some respondents gave really helpful ideas on what we could have done more of. We list a few here, but have logged all of them in appendix 2.

Direct quotes from parent carers:

“It would be good to have more access to a social setting in a rural area. I'm in Heathfield and we are cut off from everything. We are not financially comfortable and cannot afford to go too far for meet ups.”

“There is nothing you could have done better I just hope that you get the funding you need to provide these services to families. Local authority professional’s signposting basically goes "have you contacted Amaze?" which is wonderful, but Amaze needs sustainable funding if they are going to use them as the only resource for parents, often in crisis or in need of legal advice.”

“Insisted upon CAMHs being more open to assessing young people in person and lobbied to bring urgent change to a broken system - but I'm sure that work was done, I'm just not sure what.”

Direct quotes from professionals:

“Promoted online "coffee mornings" better if there were some, and allowed families unfamiliar with Amaze to join - I couldn't find details on website early in pandemic, and it seemed existing ones were not open to new members.”

“Increased educational support access - families reported waiting to discuss EHCPs and school attendance, etc.”

“Access to attendance at school – influence.”

Several of these suggestions (and others **provided in full in Appendix 1**) would have required Amaze to secure additional funding to deliver them. Amaze did bring in extra Covid-funds during 2020-22 but we were limited in what new/extra services we could provide.

Amaze has been working hard with the local parent carer forums to urge quicker improvements to CAMHS, and wider mental health provision, which families have found to be woefully inadequate. Despite additional investment from health, capacity for both assessments and subsequent support remains limited and there continues to be long waiting lists in Sussex.

So we asked parents, and professionals, to consider, more specifically, what they would like Amaze to do to support their, and their child’s, mental health.

- 50% said Amaze should provide more opportunities for CYP and (40% for) parent carers, to come together in a social setting, reducing isolation. Amaze already provides Face to Face befriending for parent carers and Amazing Futures peer support and activities for young people with SEND, so we need to consider if we can provide more.
- About 50% of both parent carers and professionals are keen for Amaze to do more influencing (lobbying) work to try to improve wellbeing/mental health services provided by others. And 40% of parents thought we should develop a counselling service. Fewer professionals thought this, maybe as they felt this was being provided by others. As a minimum, we need to support CYP and parent carers to access this, while we seek funding to provide this ourselves.

Interestingly when asked for ‘other’ ideas siblings were mentioned a few times:

“Develop a support and counselling service for siblings.”

“Offer more face to face mental health support for siblings.”

Amaze previously ran some siblings groups, in partnership with the Carers Centre in Brighton, but this funding ended. We need to seek more funding for this work, but in the meantime promote what organisations like SIBS can offer.

Direct quotes from parent carers:

"Amaze are an outstanding support network, just keep doing the great you are doing."

"Central and Local Government to be lobbied for more resources and services for learning disabilities and social care."

"Enable existing services to be more inclusive for young people with severe learning difficulties eg: attending existing or new Amaze services with a PA."

Direct quotes from professionals:

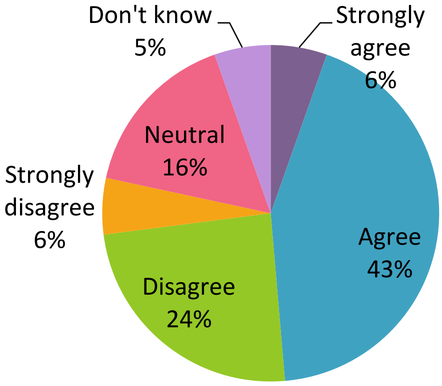
"Anything you can do to promote better education placements tailored to children's needs eg autistic young people without a learning disability."

Direct quotes from Amaze staff:

"Somehow increasing capacity in Amaze services - all projects/services are lacking delivery and management capacity."

"Collaborate with a (local) counselling service (with a history of working with people that work in the charity sector)."

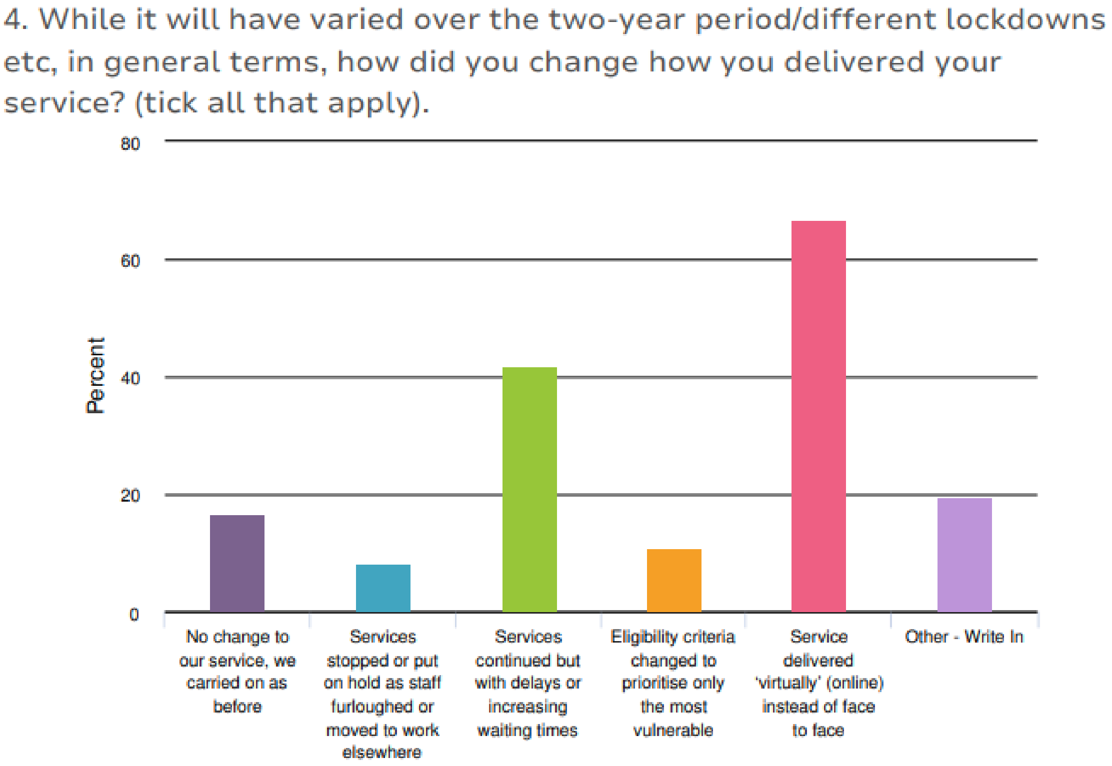
Our recent staff survey (November 21) showed that Amaze staff remain highly motivated to do the best for families, but many are reporting much higher levels of stress, due to increased and unmanageable workloads, than ever before. The below chart asks if staff feel that their workload is manageable:



We fully acknowledge that these levels are too high and is a concern as to how this impacts on staff wellbeing and their own mental health. We need to work carefully at appraisals and supervisions to ensure staff feel that their work plan/objectives are achievable and realistic, and seek increased funding to mirror the increases in demand and complexity of needs across all our services.

Findings about the Response from Schools and Other Services

Professionals were asked how they changed their service delivery during the pandemic:



We can see for the vast majority of professionals asked that services were delivered virtually during the lockdowns/Covid-19 Pandemic. For some CYP and parent carers this worked very well. However, it is important to note that not all CYP and their carers adapted well to the virtual offering. For those who did not take to virtual services we need to explore whether they were able to access services in a different way or whether they did without the service as a result of it not being accessible/appropriate for them.

Over 40% of professionals stated that their services continued but were delayed, with increased waiting times. It is interesting to note that almost 60% of parent carers said that the timeliness of assessment of their CYP education, health and care needs became ‘a lot worse’ throughout the Pandemic and almost 70% of parent carers said that access to services/support became ‘a lot worse’. From this we can assume that even though less than half of the professionals stated that their services were delayed, the impact on CYP and parent carers was reported by significantly more.

Direct quotes from professionals:

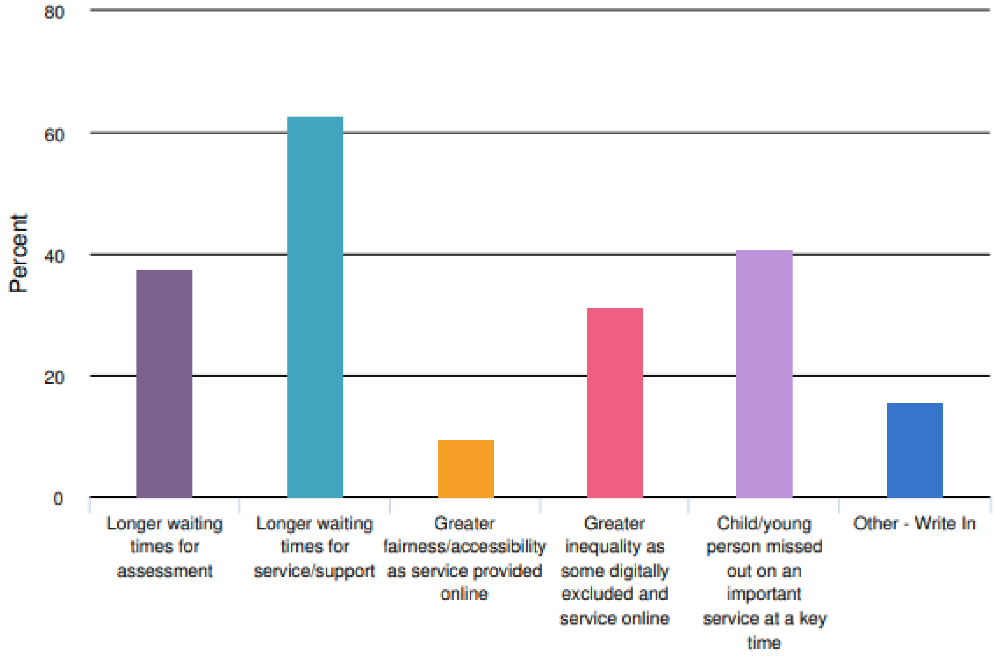
“We carried on with amended services - some online some outside some bubbles, etc.”

“We saw the most risky/vulnerable face to face at height of pandemic, rest virtual.”

“No home visits during first lockdown - service done remotely.”

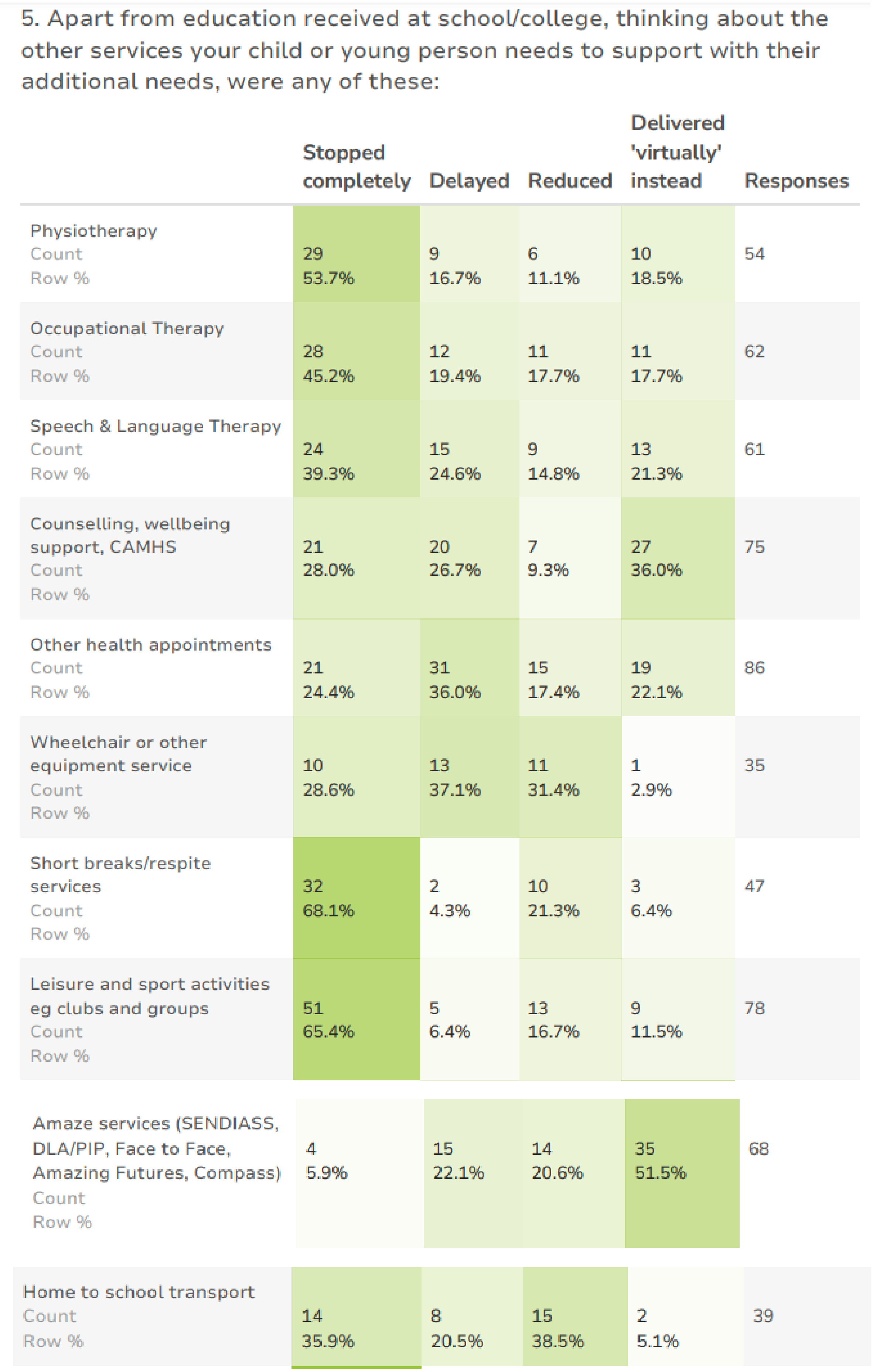
We asked professionals to reflect on what the impact of their changed service offer had:

6. Overall, what has been the impact of the change to your service (tick all you think apply)



- Over 60% of professionals reflected that CYP with SEND waited longer for support, and nearly 40% had to wait longer for assessments. This ties in with what parent carers are telling us and we need to acknowledge the ongoing impact this will have for CYP with regards to their assessments, diagnosis, treatments and therapies, as service strive to catch up with their backlogs. We know CAMHS was provided with additional funding to try to help reflect the added pressures on their services, but this has all been absorbed/spent without making much inroads into the backlog.
- 40% parent carers are naturally concerned that their child(ren) may have missed out on important services, support and schooling.

So we asked which services they felt has been delayed, reduced or stopped completely.



5. Apart from education received at school/college, thinking about the other services your child or young person needs to support with their additional needs, were any of these:

	Stopped completely	Delayed	Reduced	Delivered 'virtually' instead	Responses
Physiotherapy Count Row %	29 53.7%	9 16.7%	6 11.1%	10 18.5%	54
Occupational Therapy Count Row %	28 45.2%	12 19.4%	11 17.7%	11 17.7%	62
Speech & Language Therapy Count Row %	24 39.3%	15 24.6%	9 14.8%	13 21.3%	61
Counselling, wellbeing support, CAMHS Count Row %	21 28.0%	20 26.7%	7 9.3%	27 36.0%	75
Other health appointments Count Row %	21 24.4%	31 36.0%	15 17.4%	19 22.1%	86
Wheelchair or other equipment service Count Row %	10 28.6%	13 37.1%	11 31.4%	1 2.9%	35
Short breaks/respite services Count Row %	32 68.1%	2 4.3%	10 21.3%	3 6.4%	47
Leisure and sport activities eg clubs and groups Count Row %	51 65.4%	5 6.4%	13 16.7%	9 11.5%	78
Amaze services (SENDIASS, DLA/PIP, Face to Face, Amazing Futures, Compass) Count Row %	4 5.9%	15 22.1%	14 20.6%	35 51.5%	68
Home to school transport Count Row %	14 35.9%	8 20.5%	15 38.5%	2 5.1%	39

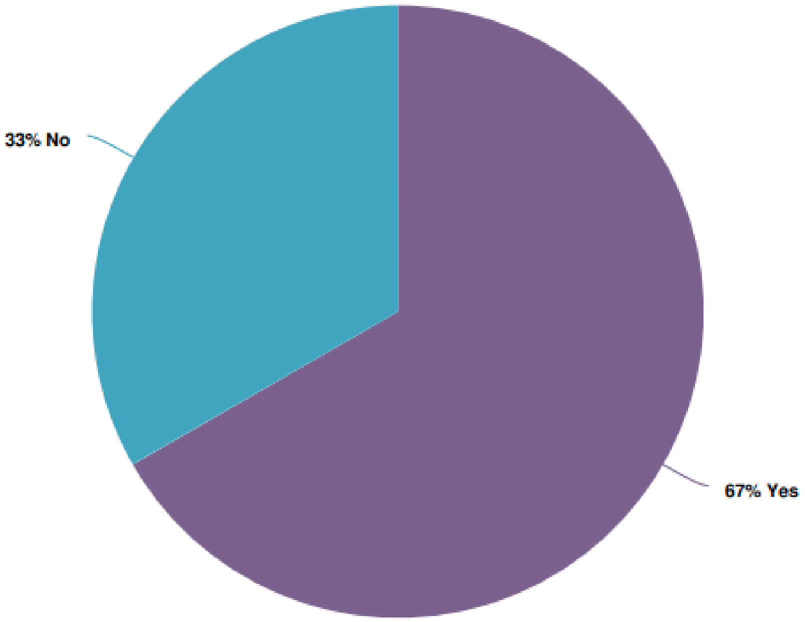
Almost 70% of parent carers told us that their short breaks/respite ‘stopped completely’. This has pushed many families, reliant on this form of support, to breaking point, and has led to the high levels of exhaustion/fatigue reported earlier.

Therapies were also affected dramatically with small numbers receiving a virtual service, 18.5% for physiotherapy, 17% for occupational therapy and 21.3% for speech and language therapy. For a lot of CYP these therapies are an integral part of their lives, allowing them to access education and, in many cases, the world around them. To have so many of these therapies ‘reduced’, ‘delayed’ or ‘completed stopped’ could have an ongoing detrimental effect on the CYP. We ask that commissioners of therapy provision and mental health and wellbeing support, invest more in these services now.

We also see that many CYP missed out on, or experienced delays to, having wheelchairs or other equipment replaced or renewed during this time, and we urge these teams to now ensure these CYP have the right equipment going forwards.

We asked parents and professionals to consider what else schools or other services could have done to support them during the pandemic:

20. Thinking back, is there anything else that you think schools, the local authority, health services, or the government could have done to better support you or your family during the pandemic – whether this is a service we could have provided, or something we could have tried to influence?



Two thirds of parent carers surveyed believe that they could have been supported better by schools, the LA, health services or the government during the Pandemic. A very similar figure, 62% of professionals asked agreed that there were things that could have been improved upon.

Some of their feedback is below, but all quotes can be found **in full in appendix 1**.

Direct quotes from parent carers:

About schools:

"The school could of rang and asked how we were doing, didn't get one phone call and my daughter was off for months. I also didn't get one call from the Choice Team - all useless!"

"School did not take into account my son's anxiety levels and change of routine, which meant he couldn't do the at home learning they provided. More communication and listening to me would have helped."

"Education for SEN Children without EHCP just left."

"There has been very little SALT input, just a couple of attachments with 2 words to practice blending, and a garden scavenger hunt! For a child who has severe S&L Disorder and provision of 9-12 hours per term, this is pretty lame."

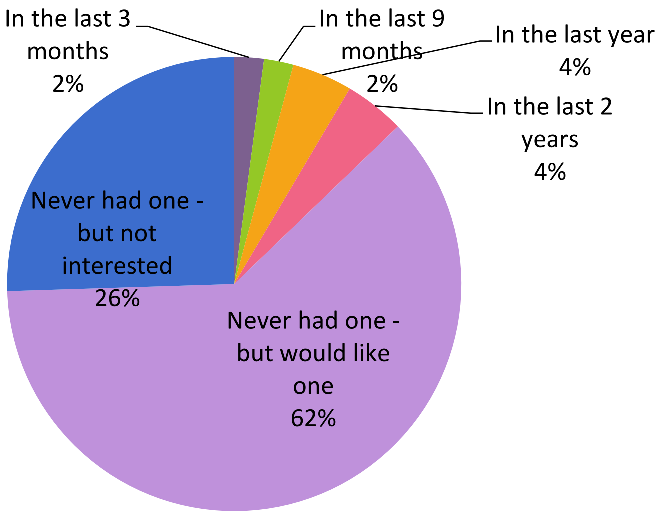
About Health:

"Medication reviews and assessments."

"GP surgeries could have seen vulnerable people and young people instead of having a telephone conversation."

"Used to have weekly OT, Physio and SLT delivered in school. This is not happening now."

Our survey to the Dad's Group in Feb'2021 asked "when did you last have a carers health check or carers assessment?" – see graph below:



This mirrors other feedback we get from parent carers that they are not (or do not understand that they are) having their needs assessed as a carer, but would like to.

About Mental Health:

“CAMHS could be funded properly so it can be accessed in more than emergencies - danger to life.”

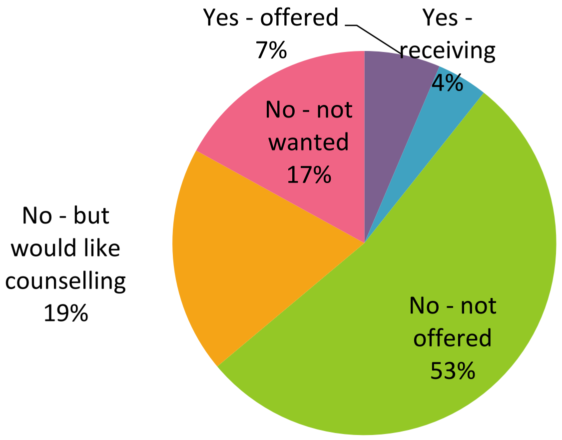
“Listen! Respond. Not parent blame. Not tell my child that he had to fit in to their model or be rejected and spat out the other side. Not make us wait for 13 different professionals to make referrals before anyone would see our son. Not telling me crisis team were unavailable to a suicidal 12 yo… Not losing his assessment. Not telling me that his MH issues were caused by autism.”

“Come to the homes! Stop telling children they need to fit in to the model of help offered and ask them what they want and need. Stop making parents wrong all the time. Listen to what they want and need! We are experts through lived experience. Stop dismissing that.”

“Sort the ADHD waiting list out… provide better pathways for co-morbidly occurring profiles like ADHD and ASC; some kids aren't one or the other, they're both. You can separate them like a clinical lab rat experiment! They're fully holistic human beings. They need an holistic approach and support.”

“Some kids were very relaxed during restrictions because they didn’t have to go through the daily anxiety of getting ready to go to school.”

We asked the Brighton and Hove Dad’s Group “Have you been offered/ received any counselling as a carer?” - only 10% of the men said they had been.



This is significant as we know that men do not readily talk about their problems. But our findings suggest, if they were offered this, one in five men would take up the offer. We would like to see men, who are registered as a carer with their GP, given the offer of counselling or therapeutic treatments more routinely if they present with a decline in their mental health and wellbeing.

As a pilot, one local CCG has just agreed funding to support three male carers the opportunity to study for a counselling qualification – to enable them support the mental health of the other dads in the group.

General Feedback:

“We (parent carers) should have had Key Worker status.”

“There were a few weeks where as a parent carer I was at significant risk of a very serious injury- I feel really cross that the government’s RAG (risk) rating system did not seek to mitigate the high risks of behaviour of CYP escalating during lockdown. The Council was unresponsive when challenged with this significant flaw of capturing need at home.”

“The local council know that I am a disabled parent with a disabled child and we felt isolated as a family as no one contacted us until nearly 12 weeks into the pandemic and still no advice given to us how to access online shopping when no slots were made.”

“Help with understanding what additional support, etc. available.”

“Due to the vulnerability of my son we did not speak or see anyone for weeks at a time. 3 months was the longest period. No phone calls. No support. No help.”

“Actually listened to what was needed, we felt very abandoned.”

“Respite care, groups.”

Additional suggestions from professionals:

“Statutory services did not utilise their staff as effectively between them as they might have. There was a lot of fear which they allowed to dictate what they offered.”

“More access to social care.”

“The government should put more funding into all services but especially mental health services for parents and young people & children.”

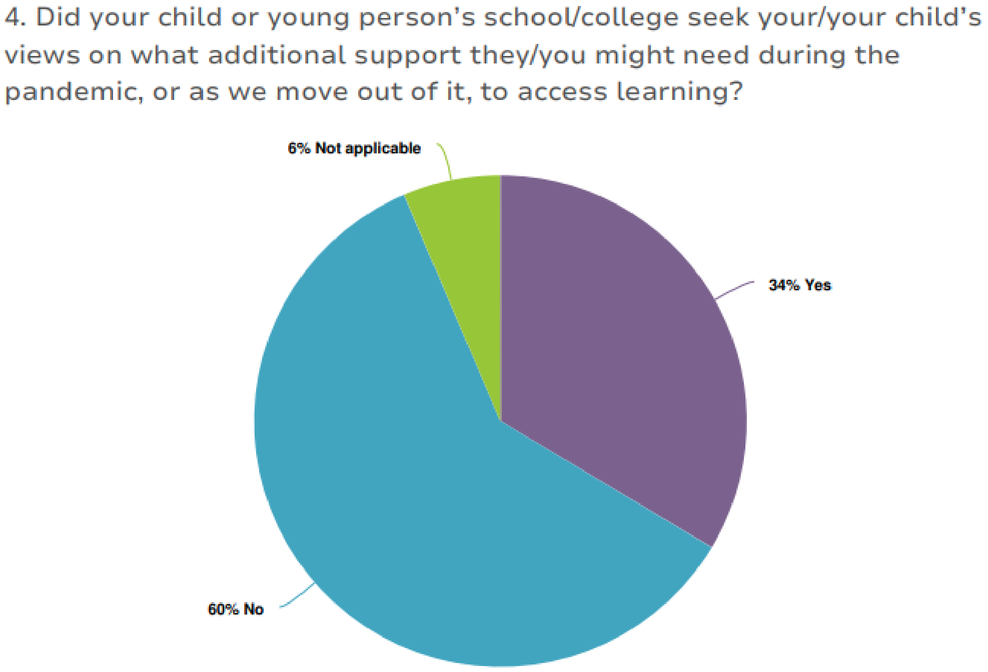
“The pandemic is still current, it has not passed, and there are still staff shortages across all settings. There will need to be a period of time post pandemic when services can reflect, as we are still dealing with issues in a fire fighting way and staff are emotionally and physically exhausted. Local services have done the best that they can however the poor handling of the issues raised by the pandemic lay firmly with the government - many of these issues... were all present prior to the pandemic but have become worse as a result of the pandemic.”

“During the lockdowns I think services were in a 'heads down' situation dealing with immediate risks, adjusting to working from home, own service pressures and we lost the opportunities for more joint working.”

“Government's support for disabled people was shocking - no money for people shielding, and now it appears they've forgotten some people are still vulnerable.”

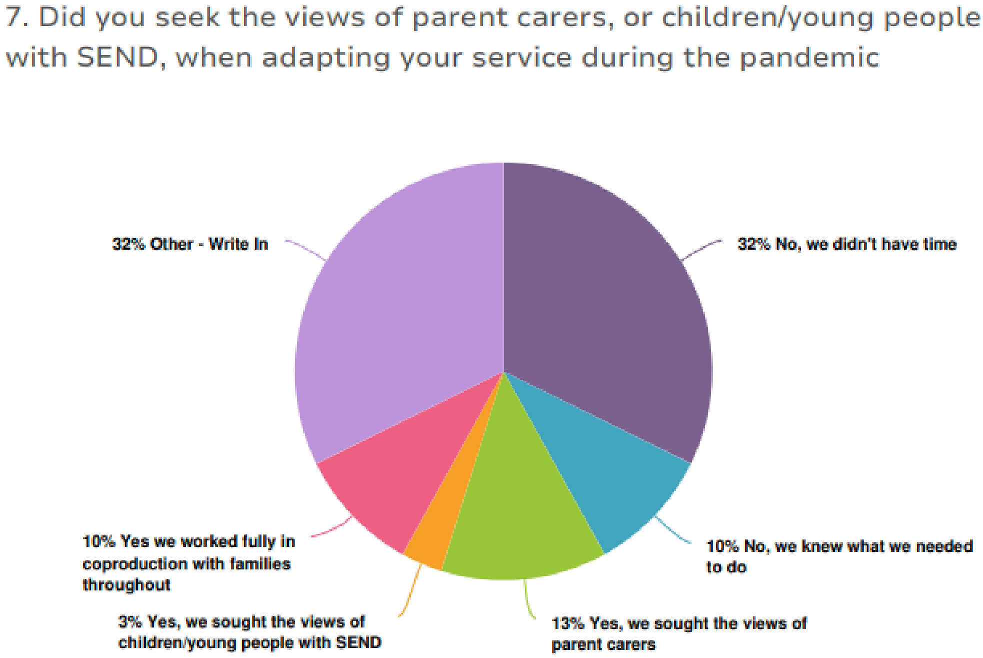
“Enabled parents to use direct payments funding more creatively.”

Only 34% of respondants said their CYP’s school/college sought their views, or their CYP’s views, on the additional support they might need to access learning:



4. Did your child or young person's school/college seek your/your child's views on what additional support they/you might need during the pandemic, or as we move out of it, to access learning?

Only 26% of respondants said their, or their child's views had been sought when adapting other services – see below:



7. Did you seek the views of parent carers, or children/young people with SEND, when adapting your service during the pandemic

Everyone had to move very swiftly to a new way of working, so it comes as no surprise that 32% of professionals surveyed said they didn't feel they had time to seek the views of parent carers. Others said:

"We had to work related to risk and vulnerability levels."

"Policy was driven from management and risk assessments of health authority and council."

It is clear that many professionals felt like they had no choice with regards to how their service adapted and it was important that workers were kept safe, particularly at the height of the pandemic. However, there were so many identified areas of need, ideas and suggestions provided by parents and professionals about what could have worked better during the pandemic, that it is tragic that their views were not more regularly sought over the last two years. With more coproduction, even with reduced services and longer waiting times, CYP and their parent carers may have received a level of service that was more responsive/appropriate to their individual needs.

Reflections and Shared Learning

The focus of this research is on parent carers, but as any parent knows, their wellbeing and resilience is much improved if the care and support their child(ren) needs is in place. As such, many of these reflections and recommendations for shared learning, concern improving provision for CYP with SEND.

a) For education

Despite restrictions being over, Covid-19 infection rates remain very high across schools in Sussex, and there remains a possibility that some schools/colleges may have to, at times, revert to a more hybrid level of working. School staff need to take this opportunity to **ensure all CYP have the technology they need at home** and ensure CYP are supported to access their education if they are unable to attend in person. **Learning should be differentiated wherever possible, to an individual's needs.**

Schools/colleges need to explore ways to keep CYP connected with their educational community, even if they are unable to physically access it.

There has been much discussion on CYP with SEND missing out on education, with many calling for **more investment to support a 'catch-up plan'** and to 'close the gaps in attainment'.

However, it is (probably more) important for schools to take the time to talk with CYP about their experience of the pandemic, home working, and their mental health and wellbeing. CYP need to have opportunities to reconnect with their peers/friends and develop their confidence in being back in an educational setting. 'The Education and Covid-19: Perspectives from parent carers of children with SEND' report (University of Sussex, August 2020) found that '**a focus on relationships, wellbeing and routine are vital components for the return to school'**. Many good schools are well aware of this, but the reality is they face competing pressures to focus on catching up with the curriculum too.

We urge schools to read the findings above and consider how they can **plan to consult and communicate more specifically with their community of SEND families**, whether this be a special newsletter, or setting up a SEND support group for families in their school, which could be used for seeking the views of CYP with SEND and their parent carers.

CYP need to feel invested in their education and connected to the setting. **CYP with SEND should always be included in EHCP reviews** and it will be important for staff, moving forwards, to give CYP choice about how to engage, where appropriate. CYP have got used to a new way of working, this may be smaller classes, additional support or home schooling. Many children have thrived in smaller groups/bubbles so schools need to be mindful that going back to big class sizes can be a challenge for some.

We know many CYP with SEND are no longer attending a school setting as they have been excluded, do not feel their needs are being adequately met, or because they have increased anxiety. Local authorities and schools need to have a **better understanding of who these CYP are, and why they are not attending school/college and focus efforts on getting CYP with SEND back into education**, with the appropriate staffing to support them.

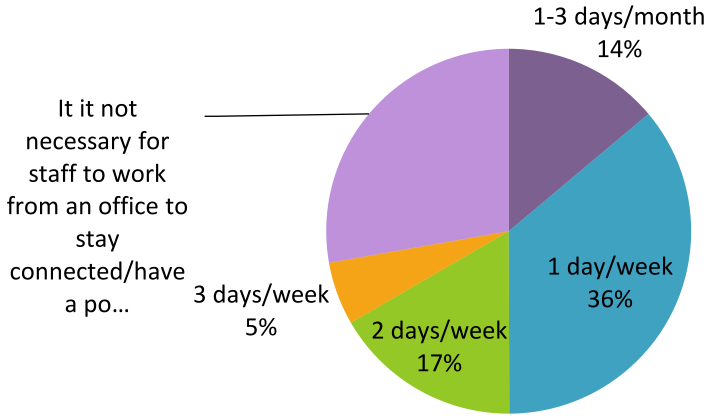
b) For the wider SEND sector

- The physical and mental health of CYP with SEND must be the main priority. Many CYP remain anxious about the pandemic so we need to ensure the **information we provide around Covid-19 is accessible** and appropriate for them.
- Work around the vaccination programme must continue to ensure that clinically vulnerable CYP and staff working with CYP with SEND, and their parent carers, get **priority access to vaccinations**, if they choose to have these.
- Greater investment is needed to resolve the concerns about CAMHS, including a systemic shift to more preventative wellbeing support.
- Counselling needs to be made more easily available for CYP with SEND and parent carers reporting high levels of anxiety.
- Need to increase opportunities for CYP and parent carers to meet up socially, in their local community, to feel more connected, and less isolated
- Clarify what support is available for managing increasing challenging behaviour at home
- acknowledge the vital role of coproduction and as such need to ensure that all service providers build in time for effective coproduction. The solutions coming from the community are usually the best, the community must be listened to and given the opportunity to work with providers.

c) For Amaze

- To consider our provision of services to YP/parents who are experiencing poor wellbeing/metal health – the additional training required for our staff/befrienders and at what point we need to refer someone with more pressing/significant needs to a more specialist MH agency. Consider developing a partnership with an established provider of counselling eg Relate/YMCA to create a better offer for our parents/YP – as waiting lists too long and people are going without.
- To build the 5-ways to wellbeing into everything we do
- The need to support staff wellbeing – as the needs of families have increased in complexity and difficulty – we have had to provide more support eg Employee Assistance Programme, reflective practice sessions (group and one to one)
- Seek more investment to provide more capacity on the Advice Line to respond to the more challenging calls we are receiving
- Offer a hybrid working model for Amaze staff - When thinking about the most effective way of working we have looked at our practice and Amaze staff were asked, how often they thought they need to work in the office to ensure they are connected, and share learning, with their colleagues, and that there is a positive team culture. Most staff think it is important to have some time (1-2 days) in the office, however, a quarter do not think this is necessary. We are moving forwards with a hybrid approach and imagine this is similar for other teams.

To ensure staff are connected and there is a positive team culture in Amaze, how often do you think staff need to work in the office?

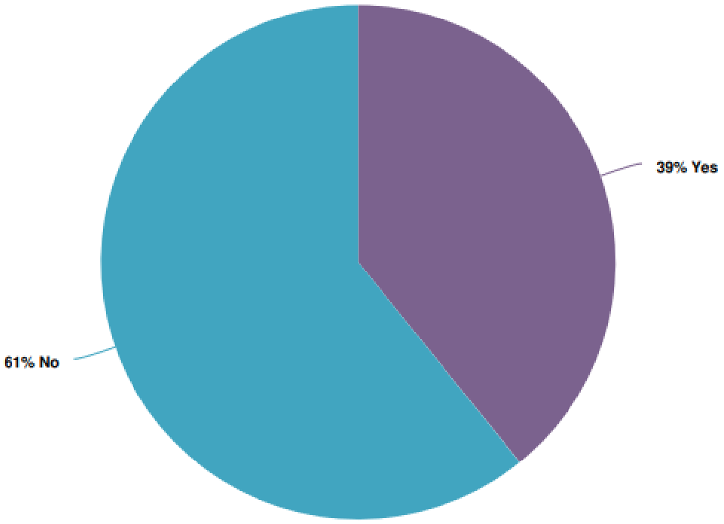


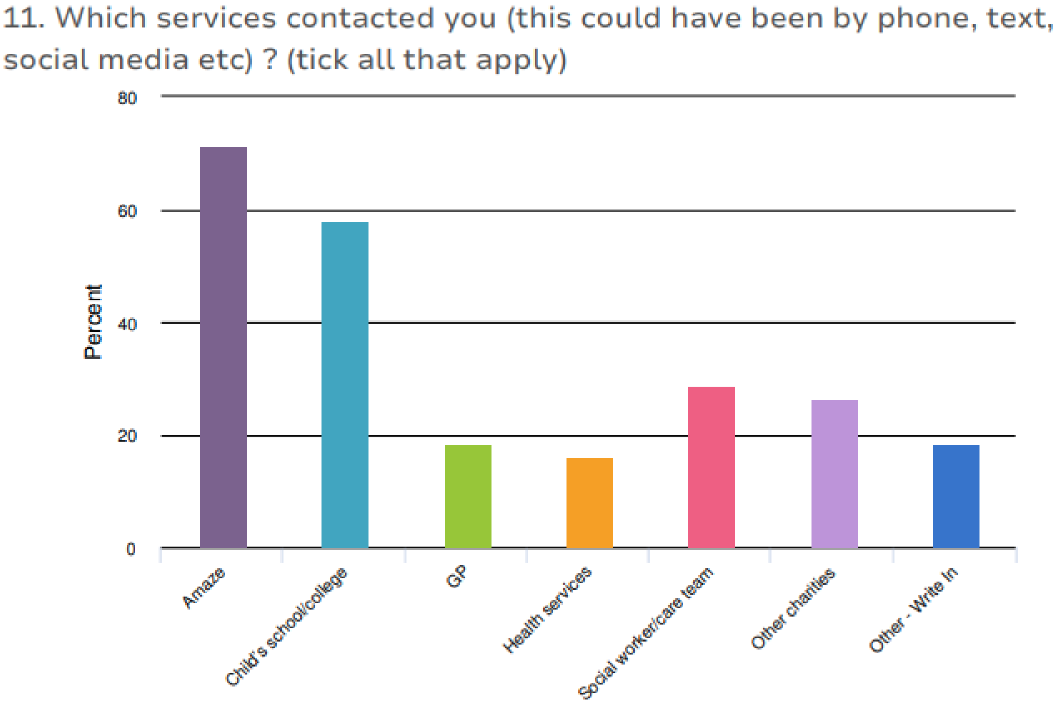
d) For us all

Increase capacity for more practive (person-centred) support calls/'check-ins'

With 61% of parent carers telling us (below) that no one contacted them to see how they were managing, or if they needed any additional support, it is clear to see why parent carers felt so isolated coming through the pandemic. Almost 63% of parent carers surveyed also reported that their connections to other people (lonlieness or isolation) became a lot worse.

10. Thinking back over the last two years, do you remember if Amaze, or anyone else asked how you were managing, or what additional support you might need for your child or yourself?





11. Which services contacted you (this could have been by phone, text, social media etc) ? (tick all that apply)

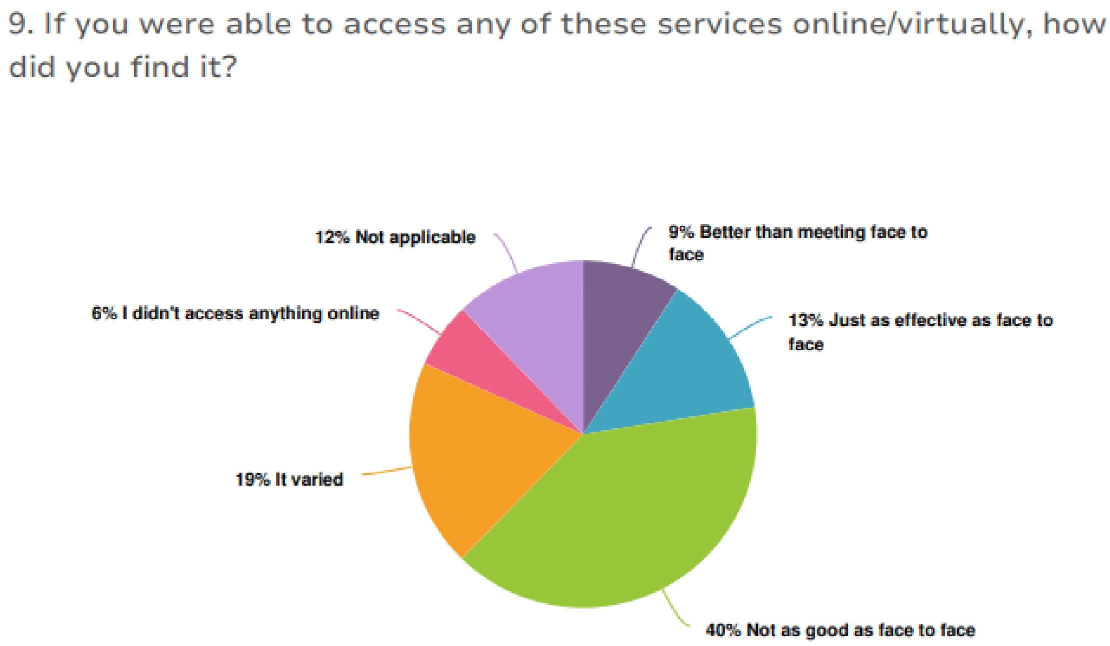
Whille Amaze did reach out to the most vulnerable families on our database, we would have liked to have had more capacity to do more proative check-in calls, and been able to follow these up weekly.

We found that many wanted to chat for quite a while, and some calls took over one hour so was a resource-heavy offer. We then switched to checking in with people via WhatsApp and many of our informal groups began supporting each other in this way. We learnt that we needed to put in place group chat rules around moderation/conduct so people felt safe sharing how they are feeling.

We need to discover (and save) people's communication preferences, so we can personalise how people want to be contacted – some prefer phone, others prefer a text, an email or a Whatsapp message. Some families do not wish to be contacted, knowing that Amaze is there as and when they need us.

Another idea is that a number of different services/teams could have come together to split out, or target the families they were going to contact (ensuring data sharing was managed within GDPR). Not only would this be more efficient, calls could be split according to the service/team who knows the family best to ensure families receive continuity and have a safe, familiar person contacting them.

Offer a personalised, hybrid service offer



- 40% of parent carers felt that online services were not as good as face to face
- 9% preferred virtual services and 13% found them just as effective.
- 38% of professionals found virtual services less effective than face to face.
- However, travel time saved for both the professionals and families was reported as a positive

With this is mind it is important for us to continue a more hybrid offering to CYP with SEND and their parent carers, that is person-centred according to their preferences.

The Council for Disabled Children's 'Lessons learnt from Lockdown' report found that 'having meetings online with professionals and support workers worked really well for some young people and their parents – reducing time, money and worry about travel. Some young people felt more confident participating in meetings online'. (CDC, 2021)

Next Steps

Our reflections, recommendations and conclusions have been summarised in the Executive Summary to this report, see above.

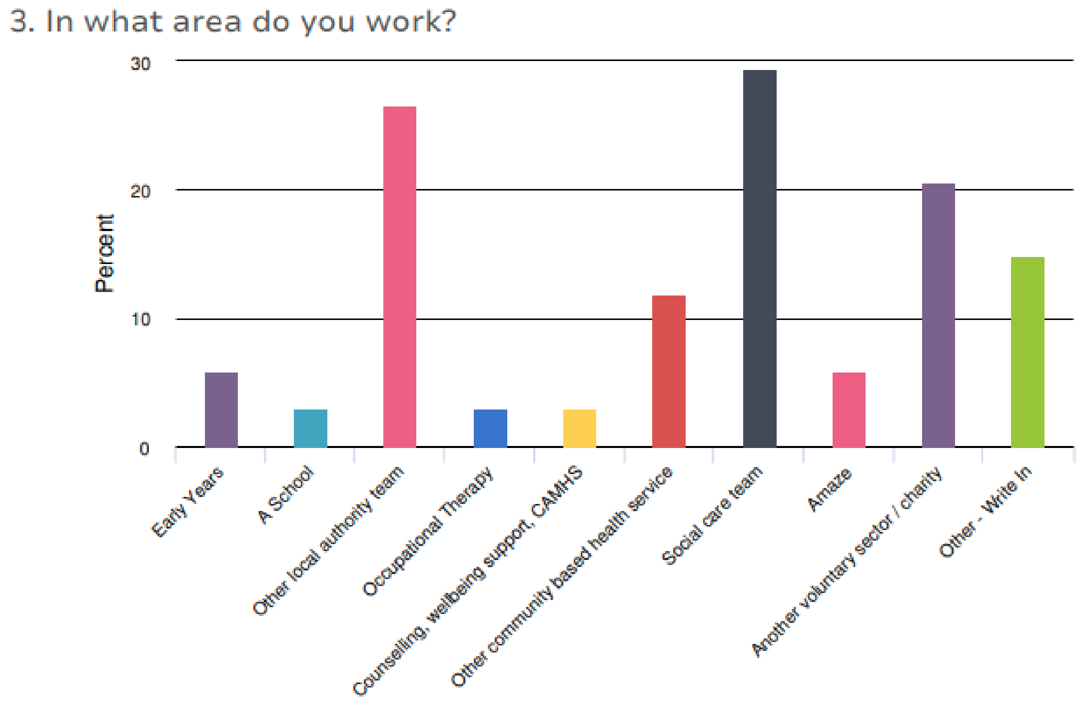
Amaze has committed to sharing this research report with our partners in Sussex and nationally, with the intention of increasing our impact from the learning - collectively improving practice for the children and young people with SEND and their parent carers who we are here to help.

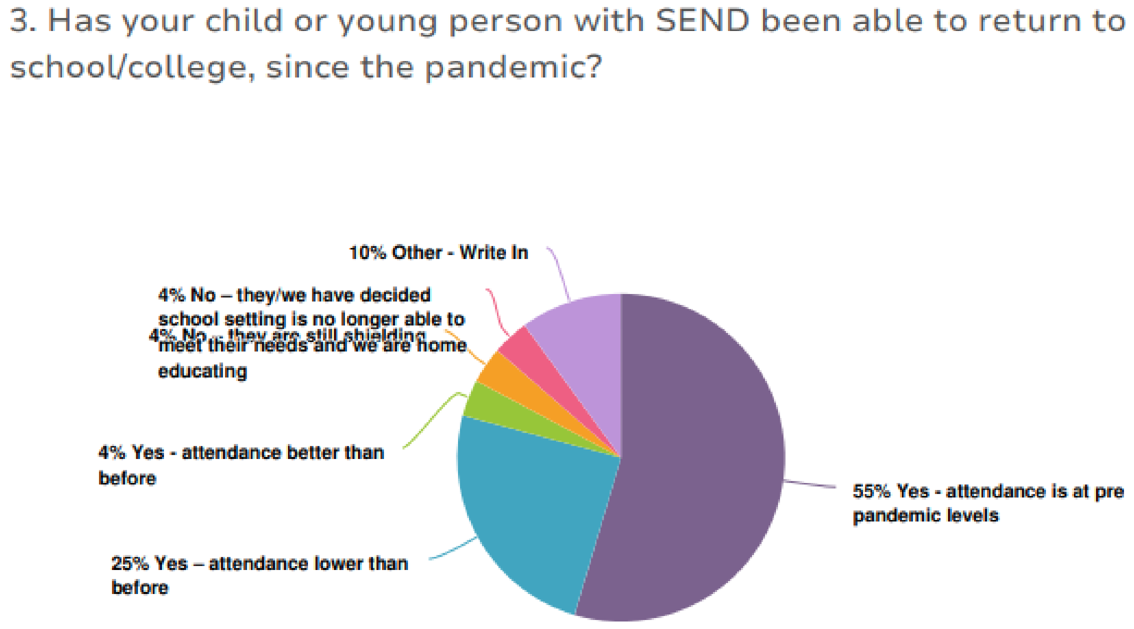
We will produce an action plan for the recommendations within Amaze's control and will encourage other local agencies to lead on the ones in their areas. We hope national decision makers will take on board the wider suggestions for greater investment, in particular in mental health services, and about prioritising all SEN-support children, if (heaven-forbid) there was ever another national lockdown.

APPENDIX 1

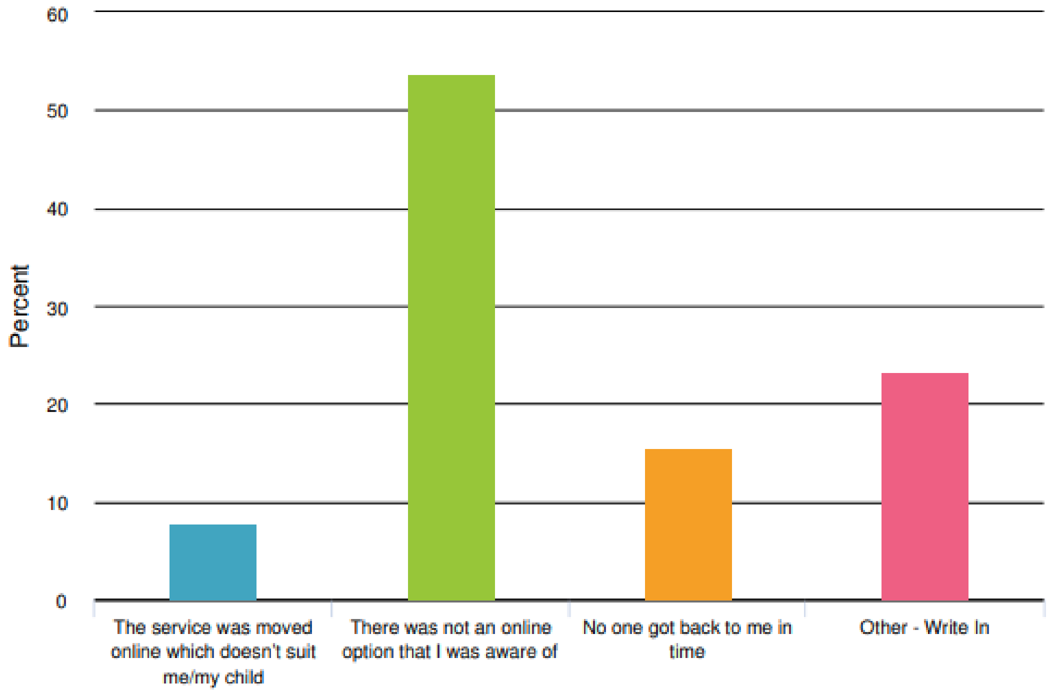
GRAPHS, QUOTES AND FEEDBACK NOT USED IN MAIN BODY OF REPORT

Graph below shows where the professionals who responded to our survey work:

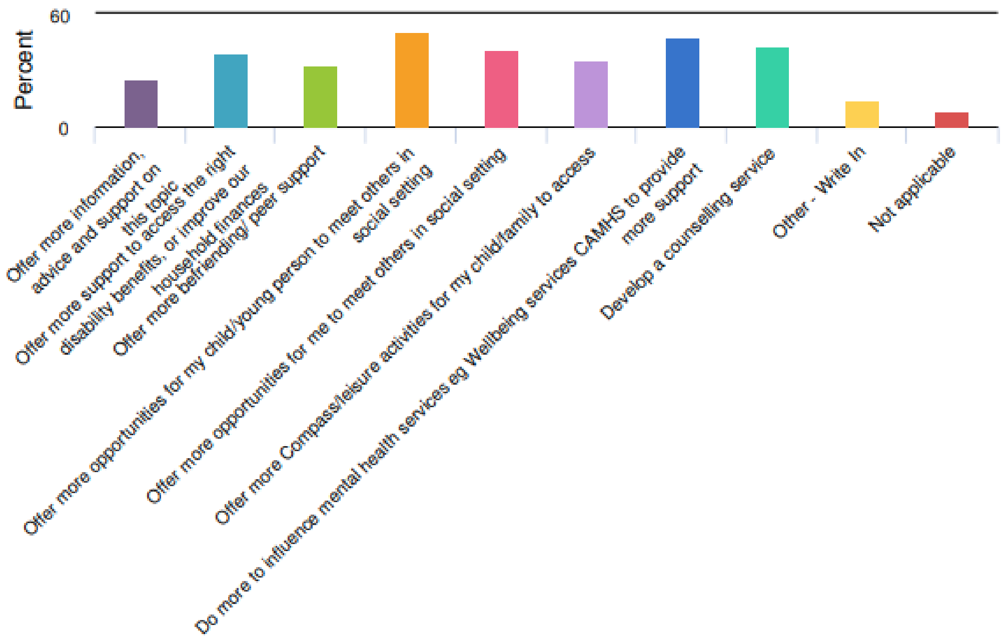




14. Why were you unable to access the service you/your child wanted?



6. We know many children and young people with additional needs, and their parents/carers, are facing increasing mental health problems as a result of the pandemic. What more would you like Amaze to do to support you with this?



<u>All Feedback on Amaze services:</u>

19. What could we have done better?

It is important for us to explore what is important for parent carers and to understand what we could have done better, or provided, throughout the Pandemic for them, and their CYP, to feel better supported.

Direct quotes from parent carers:

“Put pressure on services to provide more support for carers.”

“Make engagement much easier and simpler for people to interact.”

“Kept on reaching out regularly to all families it was a really tough time especially when schools were closed, and parents were having to work, home school and meet the additional needs of our children.”

“Publicised and sought support from parents and carers AND disabled people amidst lobbying to the Local Authority when seeking to influence the changes needed. Encouraged more engagement from the same to back up and reinforce your campaigns. Explained the reasons for, and importance of those who have lived experience to get involved /engage /tell their stories etc as much as they are able/willing, even if it’s just simply signing a petition, or allowing a quote to be used.”

“Many children in special schools were not able to access school but employers assumed if you had a SEND child they could go to school. More support and acknowledgement of that and support to talk to employers where furlough was not on offer would have been really helpful.”

“Also to connect with others during pandemic. I felt very isolated - but you may have done this and I just may not have seen it. At times there was too much info from all sources (not just Amaze) so it was hard to navigate what was most important.”

“Children support/activities, which helps parent carers immensely.”

“Telephone conversation each week.”

“Thank you so so so much Amaze, for all you've done to support us. Without your guidance I would not have come through this the way I have and been able to care for my son like we did. Most certainly he'd probably have gone in to a facility and things would have been much worse but instead I could access support and tools to do it at home, knowing I could get through this difficult time. I just wish CAMHS actually listened and were not so arrogant and dismissive. They literally have blood on their hands for dismissing and ignoring the needs of young people and the lies they've told and the parent blaming is incredible. So many lives damaged and lost due to their incompetence. It makes me weep writing about it! I'd like Amaze to sit on their board of directors as a voice of knowledge and expertise to guide and influence their decision making. I see that as an essential part of their development in providing an appropriate and accessible service for our young people and families.”

“School support for families with CYP with SEND and mental health issues was very inconsistent. Amaze and the parent carer forums could have upped the pressure on BHCC to address the risks presented by the flawed rag rating system. Senior leads at BHCC and school leads should have worked together with greater attention to the high numbers of eligible families who needed either access to a school place and/or support at home/signposting to services.”

“Access to Mental Health services. More open dialogue about the increased waiting times for medication reviews and assessments for ADHD and ASC.”

“Probably being in communication with the two SEND schools during lockdown who were appalling during the pandemic.”

“I think it was always a charity based in Brighton that I did not think reached out to Crowborough. We had previous experience re: transport to school. There were groups for parents, but seemed to be only Brighton. I was not aware of re support I could have been getting.”

“Amaze needs to have list of health professionals that other members of Amaze recommend. They need to help with finding the right professionals as NHS service is not working for anyone. The next thing is why is not working? Can Amaze help to give the right of every child for medical help and support? Also, why the mental health of the parents is not been supported by NHS. It is clearly traumatic experience.”

“Better support for shielding families, asking the LA to properly track those families, ensure that those pupil premium families were receiving vouchers, reminded the LA of their statutory duties to provide EHCP provision, ask LA to ensure children had necessary equipment to learn from home.”

“Diversifying the organisation, more youth groups, networking groups online who can't manage face to face groups, parent & child groups, increase geographical scope -Lewes.”

“But you may have done it and I may have missed it. Many children in special schools were not able to access school but employers assumed if you had a SEND child they could go to school. More support and acknowledgement of that and support to talk to employers where furlough was not on offer would have been really helpful. Also to connect with others during pandemic. I felt very isolated - but you may have done this and I just may not have seen it. At times there was too much info from all sources (not just Amaze) so it was hard to navigate what was most important.”

“Children support/activities, which helps parent carers immensely.”

“Telephone conversation each week.”

“Provide something social for children with complex needs, and their parent carers.”

“Access and referral to food banks.”

“Supporting YPs’ mental health - more training opportunities for peer supporters eg mental health first aid training.”

“More clubs/services for young people - especially those with hidden disabilities.”

“Groups for children/pre-teens.”

Focus Group feedback - What could Amaze do more of to support you or your family, as we come out of the pandemic?

- Compass card
- Face to face instead of online
- Provide advocacy for when parent carers attend meetings, a person to support, write minutes/bullet points
- In person SENDIASS sessions but also carry on providing online sessions for those parent carers who have their children at home
- Real conversations
- Portage – someone to go along with parent and child; professional to observe
- More Face to Face provision
- Family worker/key worker to help with EHCP/housing issues
- Amaze to look into if Front Door for Families can provide a case worker
- More help to deal with social services (social care services threshold too high!)
- More support
- More understanding
- Support for elderly people to offer respite / spend time with a SEND child
- Young people groups
- To create opportunities for parent carers to meet/create support networks

All Feedback on Schools and Other Services:

21. What could other services have done better?

Direct quotes from parent carers:

Schools:

“The school could of rang and asked how we were doing, didn't get one phone call and my daughter was off for months. I also didn't get one call from the choice team which is the disability team West Sussex all useless!”

“School could have done online learning. We had absolutely none in the 1st lockdown and a miniscule amount in the 2nd. We felt really detached from school.”

“Actually tried to deliver online learning in a way that was accessible to SEND pupils rather than just treating the same as all the other pupils.”

“School did not take into account my son's anxiety levels and change of routine, which meant he couldn't do the at home learning they provided. More communication and listening to me would have helped.”

“Government should have supported the schools to help them make education and care more accessible. Schools should have arranged 1:1 phone calls to homes to check in on children and support them and their families (one of my children just had badly planned worksheet after worksheet and was unable to cope with home learning).”

“More help, more school.”

“The SEN School was so bad during lockdown. No communication with families, we were abandoned with our children with severe needs. They had no initiative to move to online learning, very slow to move to YouTube, no learning packs. We fought the council for more emergency direct payments to pay for a carer full time that we needed. No support whatsoever for families with children with severe needs.”

“Accept children and have 1:1 for children with special needs.”

“Education for Sen Children without EHCP just left.”

“Schools could have been open for the children with SEN needs as we found that online zoom work was too fast paced and our child slipped further behind.”

“Better communication. Schools/therapists could have done Zoom sessions for parent carers to continue with the therapy. School said there was nothing they could provide us with for home learning as our daughter wouldn't engage virtually.”

“Our children have fallen so far behind, missed so much education. So opportunities to access education catch up.”

“Support to children to continue accessing education/school attendance should have been prioritised.”

“Actually tried to deliver online learning in a way that was accessible to SEND pupils rather than just treating the same as all the other pupils.”

“More online classes.”

“More information, training, schools not pressured children with online studying and looked at effective short notes for learning and training.”

“We could have had better support from school”

“Schools could have been open for the children with SEN needs as we found that online zoom work was too fast paced and our child slipped further behind.”

“I didn't get much help from the school. They could have supported us just even a phone call from the SENCO would have been nice.”

“Better communication. Schools/therapists could have done Zoom sessions for parent carers to continue with the therapy. School said there was nothing they could provide us with for home learning as our daughter wouldn't engage virtually.”

“School did nothing. No contact at all other than school-wide comms. We were in fact told not to contact the school for the whole of the last academic year (20-21) because they needed to concentrate on exam assessments and parents were distracting from that task.”

“School, actual support in form of call, zoom, not just a couple of pages of homework GP, access to mental health, isolating was hard and the lack of structure made hard to keep a day structure, CAMHS could be funded properly so it can be access in more than emergencies, danger to life.”

“Support non-attendance for children not at school. Home support, completing fact sheer, organisations support groups etc”

“Again activities for the children, developed with appropriate pedagogy”

“It was extremely difficult when shielding to access a learning environment for my child as he struggled with it too much. Not really sure what else could be done.”

“The school did a cursory check in but we were very much ignored by them as my child doesn't follow the learning behaviour of other children. Supermarkets only allowed us priority access at times we couldn't do. The council and CAB were impossible to reach.”

Health:

“Help provide support for medications and help with isolating periods.”

“As before - medication reviews and assessments.”

“GP surgeries could have seen vulnerable people and young people instead of having a telephone conversation and more support.”

“School, actual support in form of call, zoom, not just a couple of pages of homework GP, access to mental health, isolating was hard and the lack of structure made hard to keep a day structure Cams, could be funded properly so it can be access in more than emergencies, danger to life.”

Mental health:

“Listen! Respond. Not parent blame. Not tell my child that he had to fit in to their model or be rejected and spat out the other side. Not make us wait for 13 different professionals to make referrals before anyone would see our son and when they did it took 3m after his breakdown for them to bother. Not telling me crisis team community tram were unavailable to a suicidal 12 yo. Not lying to me. Not losing our referral. Not losing his assessment. Not telling me that his MH issues were caused by autism and because he couldn't finish his assessment due to his MH that they were unable to help. Not sit in hospital waiting to be assessed 3 times and no one coming to help him from CAMHs. Not then being told when we got home that we were at fault for bringing him to a place he felt safer and calmer than in a hospital bed feeling no one cared enough to help him. Not blaming him for a lack of engagement when finally you did see him that he rejected help due to a deep lack of trust in their abilities to put his needs first. Not then writing to me telling me I was at fault for mismanaging the service and that he seemed an articulate, intelligent young and therefore did not require further help. Not insinuating it was in my head! The service from CAMHs has been appalling and traumatising. I have no trust in them other than one mental health nurse whom was lovely and supportive once on the phone. The rest of them should be ashamed of themselves. Trying to access services since he was 8 and he's now almost 14. I've given up. If it weren't for the GP, paramedics, friends and family, this boy would be possibly dead. We had great help from BHISS, Amaze and Mascot but they absolutely should NOT have to pick up the mess made my CAMHs or fill in for their help. More on duty psych help needed urgently and in the community. Come to the homes! Stop telling children they need to fit in to the model of help offered and ask them what they want and need. Stop making parents wrong all the time. Listen to what they want and need! We are experts through lived experience. Stop dismissing that. It doesn't matter how many letters you have after your name, until you've walked beside someone in crisis like this to this extent and come through it, you have no idea how difficult that is. Listen to what parent carers are saying they need. They know the truth of the situation. Stop throwing theories and models at them that are outdated abs ineffective and sort the ADHD waiting list out! Refer to private sector provision like the rest of the country and stop the postcode lottery which puts our kids at a disadvantage for accessing these services. Also provide better pathways for co-morbidly occurring profiles like ADHD and ASC; some kids aren't one or the other, they're both. You can separate them like a clinical lab rat experiment! They're fully holistic human beings. They need an holistic approach and support. The dismissiveness of the service is appalling around this. "CAMHs don't deal with that" basically is what we were told. And then you're left cold with no options and help. Absolutely appalling with gas lighting, no follow up response to complaints, backside covering, parent blaming, child blaming (!), passing responsibility, blaming other services, lying… this culture is dangerous and corrosive and it needs to end. Sorry not sorry!”

“Stop fining/sending parents to court if their children cannot attend school because of a mental health issue.”

“CAMHS could of contacted us to let us know what is happening, and when being left a voice Mail getting back to me ASAP.”

“Not to have locked down. Caused massive mental problems not only for my special needs child but my 2 other "normal" teenagers.”

“Family mental health went down, son became more closed off, no access to mental health support through CAMHS.”

“Reduce CAMHS waiting times.”

“School, actual support in form of call, zoom, not just a couple of pages of homework, access to mental health, isolating was hard and the lack of structure made hard to keep a day structure Cams, could be funded properly so it can be access in more than emergencies, danger to life.”

“CAMHS rubbish before worse in Covid appalling now. The service that was least responsive and elastic, seemed to use their NHS status as a reason to be inaccessible SEN EHCP team almost as bad.”

General:

“We should have had Key Worker status.”

“Scrutiny of the RAG (risk) rating process was necessary. Families were at high risk of physical injury because behaviour at home of CYP with LD escalated. The children's disability team did not respond to asks for help despite sharing the urgency of significant physical injury eg: broken limbs, broken doors. There were a few weeks where as a parent carer I was at significant risk of a very serious injury- I feel really cross that the govt RAG rating system did not seek to mitigate the high risks of behaviour of CYP escalating during lockdown. BHCC were unresponsive when challenged with this significant flaw of capturing need at home.”

“The local council know that I am a disabled parent with a disabled child and we felt isolated as a family as no one contacted us until nearly 12 weeks into the pandemic and still no advice given to us how to access online shopping when no slots were made but given to elderly and families who worked with in the supermarkets.”

“Again more information on what help was available. I had no idea of what would have been available for us”

“I know that carers are overlooked, especially as I have been a full time unpaid carer for the last 7 years! I did have a career and I'm now at home with my two children with ASC. Seeing the flip side of the coin, it is very obvious that people are treated like pariahs if they are managing on money from the DWP and cannot afford to do anything. Services that are available have to be hunted for with such tenacity, that it becomes overwhelming and exhausting!”

“Help with understanding what additional support etc available.”

“Needed more people involved with us as isolated families. In the pandemic & the vulnerability of my son we did not speak or see anyone for weeks at a time. 3 months was the longest period. No phone calls. No support. No help.” “Yes there should have been support for working parents with children with SEND.”

“More regular check ins to see how everyone coping.”

“Some just left us isolated.”

“Everything. We were basic left to it and now my son is suffering.”

“Enforced lockdown sooner rather than later.”

“Actually listened to what was needed, we felt very abandoned.”

“I didn't get any support nor did my child. I feel it’s easier for them to ignore you and hope you don't ask for help.”

“Government should have made services more obtainable and more things online.”

“Respite care, groups.”

Additional suggestions from professionals:

“Statutory services did not utilise their staff as effectively between them as they might have. There was a lot of fear which they allowed to dictate what they offered.”

“More access to social care.”

“The government should put more funding into all services but especially mental health services for parents and young people & children.”

“The pandemic is still current, it has not passed, and there are still staff shortages across all settings. There will need to be a period of time post pandemic when services can reflect, as we are still dealing with issues in a fire fighting way and staff are emotionally and physically exhausted. Local services have done the best that they can however the poor handling of the issues raised by the pandemic lay firmly with the government and many of these issues-access to mental health support for adults and children, financial support for vulnerable families, poor housing were all present prior to the pandemic but have become worse as a result of the pandemic.”

“More online groups for parents to join and better direct support and advice for parents at home with their children- unfortunately the staff cohort also had their own children at home in many cases so practically this was really hard to arrange.”

“What could your/other services have done better? Children support, parent’s services, access families funding government guidance health mental pandemic staff continue vulnerable dealing direct education home lockdowns online people school schools send.”

“I feel we could have linked in better with other services to understand what they were offering, what support was available and signpost parents. During the lockdowns I think services were in a 'heads down' situation dealing with immediate risks, adjusting to working from home, own service pressures and we lost the opportunities for more joint working.”

“There were very difficult periods when the usual services that families depended on were unavailable.”

“Not had lockdowns.”

“Government's support for disabled people was shocking - no money for people shielding, and now it appears they've forgotten some people are still vulnerable.”

“There is always more to do but with funding the way it is, it's not possible.”

“Enabled parents to use direct payments funding more creatively.”

“Schools could have provided adapted materials online for SEND children. No 1:1 tuition provided. Children with SEND weren't part of the first round of vulnerable children to be able to continue attending school.”

“Given parents a break from their caring role but this would have broken government guidance. Not closed SEND schools during lockdown as they are an essential service.”

“Keeping playgrounds and equipment open for use.”

“Clearer and timely guidance.”

“Too much to note here.”

“Huge amount more could have been done, to provide more mental health support to children with ASC and SEN and to proactively support access to education during and after pandemic.”

“Collate a more structured approach to families around what guidance was available to help manage in the pandemic as guidance was coming in via different organisations and could be confusing for families.”

“Support to children to continue accessing education/school attendance should have been prioritised.”