



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on top of the disproportionate impact of rising fuel prices on disabled families, and the Universal Credit uplift being withdrawn.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 isolated, 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."*

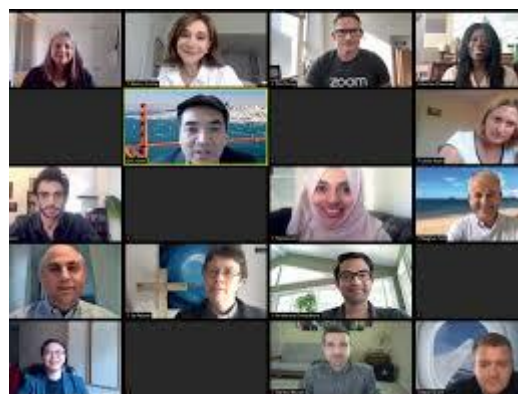
#### **e) Some services were quicker to adapt and were more person-centred, flexible and understanding than others.**

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.

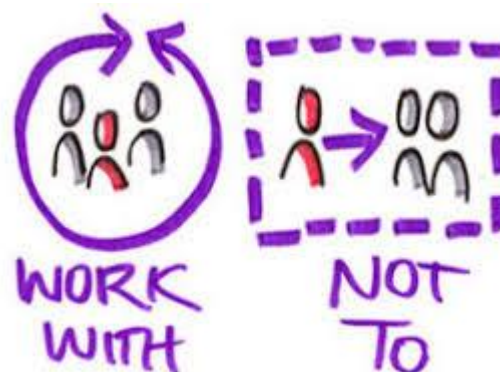


**g) Understandably, services were in crisis mode, but more should have paused to ask parent carers to identify needs and co-produce solutions**

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:
  - o Review our provision of services to young people/parents who are experiencing poor mental health and seek new funding partnerships to provide 'early help' support
  - o 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 isolated, 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:
  - o 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.
  - o 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 here:

<https://amazesussex.org.uk/wp-content/uploads/2022/06/FULL-report-on-impact-of-pandemic-on-parent-carers-NHSE-v2.pdf>

