

newsletter

July/August 2020

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If there are issues you would like to see in future newsletters, contact comms@ familyvoice.org.uk or leave a message on 07950 302937.

In the hope that gatherings will be possible next year, please save the date...

> Family Voice Norfolk Conference Saturday, 13 March 2021



Learning Disability Annual Health Checks

From the age of 14, young people with a learning disability are entitled to an annual health check. This can continue throughout their lives.

The first step is to make sure they are on your GP's register as having a learning disability. You may need to ask for the health check but many GPs will send you an invitation anyway.

The health checks are a national entitlement, brought into being to address the fact that people with a learning disability have shorter life expectancy and poorer health outcomes than average.

Family Voice representatives have been working with health professionals for a while to make sure that families know about health checks and that the checks themselves are as useful and easy to access as possble.

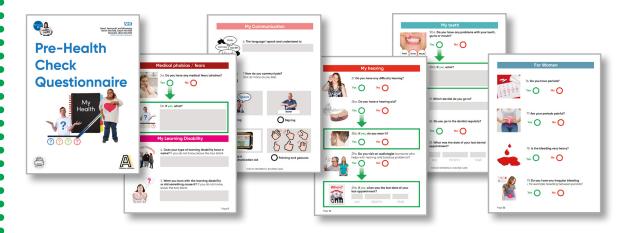
LD Health Checks and COVID-19

The situation at the moment – as for many health issues – is complicated. Some GPs are offering face-to-face health checks again, others have not yet restarted or are only offering telephone appointments. You will need to contact your own surgery to find out what is happening.

A recent development is that GPs have been sent a **Pre-Health Check Questionnaire** booklet to be filled in by the person with a learning disability before the appointment. Some are already using this and we would recommend asking about it if your surgery is not. The booklet has 40 pages but can be filled in with support from a family member or carer and is in easy-read format. It covers lots of subjects in a simple and straightforward way. These include health issues, of course, but also important questions such as what kind of support the person has, how they like to communicate and their living and working circumstances.

Filling in the booklet with my son was a good experience. It gave us the chance to talk about his health and discuss areas where he would like more independence and where he feels he needs support.

The health checks help my daughter to feel confident that the surgery is somewhere that understands and will help her.





Join us in an online get-together to:

- Ask questions in a relaxed setting
- Share ideas with other parent carers
- Make sure professionals know what families need

with Tim Eyres

Assistant Director for Commissioning and Partnerships, Norfolk County Council

Monday 7 September 10:00am to 12:00pm

Find out how your input can help shape services for young people with SEND.

Contact Bernadette at office@familyvoice.org.uk for joining details.



Join us in an online get-together to:

- Ask questions in a relaxed setting
- Share ideas with other parent carers
- Make sure professionals know what families need

with Rachel Gates

Strategic Health and Disability Commissioner, Norfolk County Council

Wednesday 7 October 10:00am to 12:00pm

Find out the latest news on Short Breaks services.

Contact Bernadette at office@familyvoice.org.uk for joining details.



Family Voice ... representing your family

If you are reading our newsletter for the first time or are new to the world of special educational needs and disabilities (SEND), you may not know that **every single one of our representatives**, attending meetings with service-providers, commissioners, decision-makers, health professionals, educational and social care practitioners and voluntary organisations, is the **parent carer of a child or young person with SEND**.

Our children have different needs and challenges, but we all understand in our own lives the massive difference that well-planned services, easy-to-navigate systems and straightforward communications can make to our families. That's why we do what we do. We are not a support group and we are not an information service, but by speaking up about what our families need, we aim to ensure that **you** are supported and **you** are informed.

Please help us to speak up for all our families by:

- telling us about your experiences the good and the not-so-good;
- telling friends, family, teachers and other professionals about us;
- thinking about whether you might like to join us in representing the views of families like yours.

We are all experts about our own children and the needs of families like ours in a way that most professionals can never be. They need us to speak the truth about our lives and our children need us to speak up on their behalf. We offer training and mentoring and understand the unpredictability of family life. We would never ask you to commit to more than you are able to. Contact us by any of the ways on page 15 and have a chat about how you can be involved.

Disability Pride 2020

Due to the pandemic, subsequent lockdown and guidelines, the difficult decision was taken earlier in the summer to cancel the physical Disability Pride. Undeterred, Equal Lives and supporting partners Active Norfolk, the UEA and the Human Library are going to be bringing Disability Pride online. The event will be over the month of September and will be kicked off by a message from Disability Pride Chair Martin Symons, welcoming everyone to the digital event. There will be performances, poetry, activity demonstrations, talks and lots, lots more. For a glimpse of what will be in store click on the link below:

https://www.norfolkdisabilitypride.org.uk/dp20-online-covid19

Family Voice Norfolk had a stand at the physical event last year and we look forward to being able to do so next year (fingers crossed). It is such a fantastic event and the spirit of Disability Pride will carry on digitally for 2020.

SEE YOU THERE!







First Response/Call: 0808 196 3494

A 24/7 service for people of all ages in Norfolk and Suffolk requiring mental health care, advice and support.

Help in a crisis 24/7 helpline

First Response is a 24/7 helpline offering immediate advice, support and signposting for people with mental health difficulties.

If you are experiencing something that makes you feel unsafe, distressed or worried about your mental health you can now call the helpline on 0808 196 3494.

Who can call?

The helpline is available to members of the public of any age, regardless of whether they are an existing NSFT service user.

The line is also open to other healthcare professionals, such as ambulance staff and GPs, as well as social care colleagues and police personnel who may need advice when working with individuals who are undergoing mental health difficulties or may wish to refer someone.

What happens when I call?

Your call will be answered by a trained mental health professional who will be able to listen to your concerns and help you get the support you need.

Callers will hear a recorded message instructing them to press either 1 or 2, depending on whether they are a professional or member of the public, and will then be connected to a mental health practitioner.

What if I want to remain anonymous?

If you would prefer that the person answering your call doesn't see your telephone number, you can turn off your caller ID in your phone's settings.

Find out about this and other NSFT services at https://www.nsft.nhs.uk/Find-help/Pages/ Helpline.aspx

Your feedback would be helpful

NSFT are working with Healthwatch to find out about your experiences. You can click on the Norfolk link (https://healthwatchnorfolk.co.uk/services/first-response-by-nsft) to give feedback.



September 2020

The next newsletter will appear in September 2020. If there are issues that you would like to see covered, please email covered, please emailto: covered, please emai





A record for FVN's Membership Secretary...

Kate, who has been Membership Secretary for eight

years, reports: this year I welcomed the parent carers of our youngest child ever. The little one was diagnosed with a learning disability before birth and his parents embraced the idea of being part of the SEND community and became members.

Their son made an early appearance, just before our annual Conference in March, meaning that his parents weren't able to attend as planned.

When we say that we represent families with children and young people with SEND from 0 to 25 years, we really mean it!

A record for FVN's reps...

Our Administration Assistant Emma receives requests for representatives to



attend meetings (or chases organisations to invite us), finds which reps are interested and available, and organises all the paperwork, online links and reference material that reps need. It's always a busy job but in July she sent representatives to 67 meetings – a record month for Family Voice Norfolk. As all meetings are online at the moment and rooms don't need to be booked, meeting requests can be at very short notice. Afterwards, there is feedback to collate, minutes to file, follow-up meetings to organise and information to be shared. August has been a little quieter, but September certainly won't be!

Football-based activities for children with SEND

The Community Sports Foundation, Norwich City Football Club's charity partner, has developed an online portal of football-based activities that children can do over the



summer at home or in the park, and even better, they will be providing the first 50 eligible applicants with a Norwich City football to do it with!

All parents and carers need to do is compete the form at https://forms.gle/6t85KNe1AbqpSRbdA and CSF will post the ball out to you directly. Even if you are not lucky enough to grab yourself a ball, you will be able to access the activities via https://apps.



This offer is strictly for children with special eductional needs and/or disability (SEND) aged 6–11 years of age, to ensure the limited amount of resources are provided to those who would benefit most at this time.

Find out more about CSF's COVID-19 community projects and their plans for the new season at https://www.communitysportsfoundation.org.uk







(ALLING DADS!

Are you a dad in Norfolk whose partner breastfed your baby?



We want to know what support YOV had as a dad...

What helped or what could have helped you more to be able to support your partner and new baby?
We are holding 2 focus groups to discuss what went well or not so well for you with other dads.
Chat to us online and help us to help you and future dads.

The sessions are friendly and informal.

Thursday 3rd September 7pm

Join us by using this link: bit.ly/norfolkmeet8

Thursday 17th September 10:30am
Join us by using this link: bit.ly/norfolkmeet9

To find out more contact Michelle on 07833524216 or email michelle.walker6@nhs.net

JustoneNorfolk.nhs.uk

Family Voice Members Chat Room – you said, we did...

Our closed Facebook group called **Family Voice Members Chat Room**, where full members of Family Voice can share freely in a safe environment, is growing in popularity and has already strengthened our contribution in meetings with the local authority, health and voluntary services. Here are some of the topics that have been discussed in July and how we have been able to carry them forward – always anonymously unless a parent carer specifically grants us permission to give further details.

• EHCPs and Annual Reviews – how have you found engaging with EHCP Coordinators over the last couple of months?

13 months to get EHCP. The hold up was educational psychologist, then the coordinator to write it but had to complain in the end. Then a different coordinator wrote the plan, then annual review she didn't turn up because she told the school that she was leaving in 2 weeks ... new coordinator seems nice but I think that is going to change person again ... The issue was placement.

Ours was all done in 18 weeks. Our coordinator seemed to know what she was doing and when we questioned aspects, we were told "this is just until her ASD diagnosis is finished. Then we will update it". It wasn't updated and we've just had to have an emergency review to get it changed. The review was fantastic. Luckily, her current SENCO is on it!

Both of my children's EHCP process were relatively smooth; thorough & resulted in well-written plans. We had different coordinators as well; both were very helpful & readily available if I needed to contact them. My main concern is with the school actually following it!

This week after a 4-year relentless battle, Mediation and also Norfolk Parent Partnership advice along the way, finally my child has an EHCP that gives her all the provision she was identified as needing in a setting. Hurrah! It has been a tough road but the outcome is what she needs and I'm really happy

I'm having to call an emergency EHCP review, due to NCC's inability to source a suitable school. SENCo is inviting EHCP Coordinator and asked who else we want there. Who should be there? Who can help us? It shouldn't be this hard. It's basically starting the tribunal process. I'm not sure if I can fight much more. My mental health has deteriorated so much. I'm not living; I'm existing.

We've been waiting a year and a half for our son's school to actually do the EHCP application. It's been hard work!! Norfolk SEND partnership have been helpful throughout and the SENCo emailed a couple of weeks ago after epic mailing from me in lockdown, saying that he has started it. I'm not filled with hope and am dreading September...

Family Voice Norfolk: the Education, Health and Care assessment and plan processes are one of the areas of 'significant weakness' identified by Ofsted/CQC during the Local Area SEND Inspection in March this year. We have been representing families' views at meetings with the local authority, health service, other professionals and other parent carer groups. Although there is no doubt that Norfolk's record in keeping to the statutory timescales is very poor, your feedback about what particularly concerns you and where things go wrong has been enormously helpful. Please keep telling us what is working or not working for you in the Chat Room. The 'written statement of action' that Norfolk has to send to Ofsted in early September will be influenced by what you tell us.

• EHCP Coordinators – your experiences in the last couple of months

I've just found out that my EHCP Coordinator hasn't updated the records with my daughter's official diagnosis. No wonder the ASD schools have turned us away! So battling for a school for 6 months and they aren't using the up to date information.

My son started last September in a special school 6th form, entirely new school to him. When I went for annual review at new setting, they hadn't been sent latest EHCP by coordinator and were working from old one. Review therefore a fiasco and he won't have had one since he started.

Mine has made herself completely unavailable and the school have no idea how to get in touch with her...so not good!

They have managed to make contact with 'someone' but no one appears to know the whereabouts of the coordinator. School not impressed.

Family Voice: these specific issues, of course, are included in the work mentioned on the previous page. The picture seems so uneven – excellent work by some Coordinators and huge frustration for parents from others. A further area of weakness identified by Ofsted was communication and co-production with parent carers. We continually stress that straightforward, clear communications and someone to talk to on the end of the phone are essential for parent carers navigating complex systems.

COVID-19 and return to school in September

We are dreading our son going back in September. He hates his school, even the thought of it gets him stressed, and he bites and sucks his arms. I have spoken to the SENCo as he is aware of how much our son hates the school environment in normal times and how impossible it will be for him to sit still and social distance so will be putting something in place, apparently. I don't know what ...

My son (at special school) had letter today to say he will start back on 2 days a week in September.

My daughter ... in a special school will be attending full-time in September. However, they will be finishing the day at 2pm for cleaning.

My sons letter says full-time from September 7th but only because I wrote to my MP who wrote to school as they initially said part-time 5 days over 2 weeks

My little boy starts at his special needs school in September. They have said it will possibly be part-time to start with while they are in there bubbles.

My daughter is at a special school. We have had a very detailed letter, about a part time return to school for the first four weeks of the new term, she will go in three days one week and two the next, so the class will be split into two and it will be reassessed after week three, no uniform, and no hot dinners.

Our son is due to start at a Special School in September. We too, have had a very detailed letter about his return. I work 5 days a week from 8-1 and have had to put in an application for flexible working during September so that I can be at home with him on the days when he is at home, which I'm hoping they'll accommodate.

Family Voice: we have been working with the local authority on the COVID-19 recovery plans and will be grateful to hear more of your experiences as your children return to school.



• Preparing for adult life – what is your experience with teenagers and young adults?

How can our children become successful adults (as successful as neuro-typical children their age) when due to lack of SEN provision, many spend months, even years missing education or in inappropriate settings?!

I'm really concerned when my lad finishes college next year he will have nothing meaningful to go onto?

No one is checking when our youngsters finish education at 25 what they move onto if anything? Or indeed what they might be doing at say 30? All very worrying especially as we live in a really rural area!

In west Norfolk, there is NO educational provision for students with severe autism, SLD and complex needs post 19. They fall off a cliff since Plaxtole house closed. Extensively, there is NO educational provision post 19 for SLD here.

Many of my friends are not receiving transport from NCC for all their adult child's days in settings. They are being refused it and so are having to drive their adult child, often across the county themselves in order to access things. Then hang around in that area for hours as no point driving back only to go back again.

No educational provision for non-verbal learning disabilities/autism local to Kings Lynn. Accessing suitable day services/care farms requires transport being available. As a single parent who has to work to meet financial commitments and has a right to a life, I can't physically/psychologically be expected to provide it.

Our entire lives are taken up with trying to source adequate onward services. Day services/colleges/ PAs etc etc... all of the above and more... there is NOTHING in West Norfolk suitable for those with severe autism/complex needs. I challenge you to find something in our 'locality'... the lack of support and services gave me no choice but to choose residential. My son has just turned 21

Our son is year 11 in Sept and out of county, I see nothing for him to come back into county for at all post 19, especially as there is nothing in the West here in particular. We want him to have education still, worthwhile quality education and life skills and as he is severely autistic, there is nothing. I don't know how many times NCC are told this every year by parents but still nothing is done. Day Centres are not educational for his level and not accessible. They won't take him as too high level need and will be 1;1. We started investigating adult options over a year ago as we prepare early... and there is nothing.

My son is lucky enough to have found a full time job (after 1 supported internship and 2 apprenticeships). Unsurprisingly, transport was not available for any of these things, his job is 10 miles away over the border in very rural Suffolk. He cannot drive or safely ride a bike. He cannot pay for taxis from his minimum wage – only option = Mum! Thought needs to be given to how aspiration is supported, getting a job is one thing, getting there is quite another, my only realistic working hours are now 10:30 - 4:30.... makes it really difficult for either of us to be financially independent ... unsurprisingly I chose him!! Transport is always a problem.

Family Voice: another area identified by Ofsted and one that has many different strands: education, training, employment, accommodation, community involvement, health – and all of these raise multiple further issues. The support young people need is so varied – it really is vital that provision is person-centred. Many parents foresee years of continuing care at home when both they and their young person long for alternatives. This is a huge subject with no easy fix, but we are speaking up in all relevant meetings about the real experiences of so many families.

• Communication with health professionals – what is your experience? What do you want?

A professional said 'so what does your daughter do that other 8 year olds don't do?' How would I know that! I only know what she does! And, it is so difficult to talk about them honestly when the child/ YP is in the room with you, so an appointment or at least part of an appointment where they are not with you!

Not to have a professional talk about your child or young person as if they aren't in the room or don't understand what is going on. Treating the child or young person with the same respect, dignity and courtesy as you would pay anyone else is absolutely vital. We had a geneticist eyeball my child, look at me and ask "So how bad is he then?!"

That they actually take a while to read the notes and not launch into, so tell me your story!

Agreed that they should read notes first! In addition, that professionals, who are not qualified to do so don't make statements. Eg the cardiologist who began an on-file letter 'This highly intelligent young man...' (because he nodded in the right places) and a dentist who bounced him from a service because they asked him 'Can you do ... without difficulty?' And he said, wanting to please, 'Oh yes!' A quick look at his notes would show that he can't.

More tact and respect within the appointment for our child as he understands everything so on occasion my husband has taken our son out while I've spoken to the paediatrician...

More detailed reports when you have had an appointment as we have had really long appointments and a lot of details given but when the report comes it's a couple of paragraphs without the details.

And a letter before to know what is going to be asked so we are prepared for the appointments as time between them is very long so everyone can get the best from the appointment.

Family Voice: our representatives attend an increasing number of health meetings, including the Children and Young People's Health Network meeting, work on Learning Disability Health checks and (when we are not in the midst of a pandemic) helping trainee nurses to understand issues like those above. Sometimes just a small shift in attitude and approach can make all the difference to us and our children – we will continue to educate those who do not live our lives.

Speech and language therapy (SaLT) – have you received a service since lockdown?

Just found out that face-to-face SALT provision will not be happening until January 2021 at the earliest. I can accept that if remote provision will be offered as a temporary substitute, but it still isn't happening. That means that we will have minimum 10 months of no SALT provision, & this is after our 3-year fight to secure this provision after not receiving SALT. We have it written in our EHCP, & don't feel they are making any reasonable endeavour to provide the SALT service.

We sat on a waiting list for SALT for over a year. We finally had a call in June to say my child was now at top of list but not offering any appointments at the moment. ... My child barely says a word, and will be starting school before we get any SALT underway ... at this rate! Why can't they offer digital appointments ... What's the issue?

Family Voice: our representatives attend both the Speech, Language and Communication Network (SLCN) meetings and the Children's Health Integrated Commissioning Group (CHICG) meetings and have raised parent carers' concerns strongly at both. We will be continuing to press for movement on SaLT, particularly given the government's statement (see page 29) that 'Our focus will increasingly be on supporting local authorities, health bodies and schools as



they work towards full provision being restored for all children and young people with EHC plans. We are calling on local services to prioritise support to children and young people with SEND so that they are able to access their usual therapies and other help they need to be in school.'

• Young carers and siblings of children and young people with SEND – how has lockdown affected family relationships and responsibilities?

Our SEND child is the eldest. His two brothers have been with him 24/7 since March ... Our days are dominated by him. Got me thinking about what life is like for his brothers as young carers really, helping to keep him happy, safe and having to take a back seat at times. I am really keen for them to really know what they can access support-wise if they would like to. I wonder if there are many families who haven't known how to find out about Young Carers groups?

I have been thinking this a lot lately. Observing how my ASD daughter controls so much including me at times and the way she speaks to and manipulates and coerces her younger brother into doing things her way or no way. It's so hard.

Our Son who also has ASD and ADHD came along when the others had left home, but he has controlled all of our lives in some way or another! To the point of where and who we holiday with, and what we can and can't do when we get there.

My 2 have been meeting at Boom every 2 weeks for 1–2 hours, they are doing online things. I bet there's loads of families who don't know anything about young carers. My daughter is a part of the Norfolk carers forum and went to the carers festival last year.

Son diagnosed but my daughter is awaiting diagnosis. I think it is important for them to have time away from each other...

My friend runs the young carers group 'Connects & Co' Their mission is to provide emotional and practical support for children and young people aged 5 years to 25 years who are affected by the illness or disability of a family member.

Family Voice: as well as the concerns above, many families recognised that they needed to consider what plans they had in place if parent carers were unable to care through illness or simply Covid-19 restrictions on travel or gatherings. We featured some information for and about young carers in the last newsletter (June: available on our website at www.familyvoice.org.uk) and there is a young carers strand to the COVID-19 Recovery Programme underway in NCC. We have a representative in these meetings, which have been looking at issues such as:

- The role of sibling carers as well as young carers and how they take a back seat in terms of opportunities and attention.
- Have schools been proactive in the COVID-19 period in supporting young carers? Schools do
 not have to record young carers, but are being encouraged to apply for the Carer Friendly tick
 award and be more proactive in their approach.
- A young carer emergency planning document similar to a one-page profile is being developed with input from Family Voice.
- Do young carers have access to a carer's health check?

These have been weekly meetings that have included young carers themselves. We will also be involved in a wider discussion with representatives from other forums in the Eastern region.



Free workshops for parents and carers



Contact, the charity for families with disabled children, is running a series of workshops for parent carers – all accessible online via Zoom. Full instructions for using Zoom and accessing the workshops, together with booking forms and further information, is available if you click on the links below. NB Although the links mention 'West Mids', these workshops are fully available to parent carers in Norfolk.

Encouraging positive behaviour in children Tuesday, 1 September 2020 12:00–14:00 https://www.eventbrite.co.uk/e/encouraging-positive-behaviour-in-children-west-midlands-tickets-114444809506

Helping your child sleep Tuesday, 8 September 2020 12:00–14:00

https://www.eventbrite.co.uk/e/contact-online-workshop-helping-your-child-sleep-west-midlands-tickets-114471364934

Encouraging positive behaviour in children Wednesday, 9 September 2020 19:30–21:30 https://www.eventbrite.co.uk/e/encouraging-positive-behaviour-in-children-west-midlands-tickets-114475858374

Money matters Thursday, 10 September 2020 10:00–12:00

https://www.eventbrite.co.uk/e/money-mattersfor-parentscarers-of-children-with-additional-needs-westmids-tickets-115293814904

Money matters Tuesday, 15 September 2020 12:00–14:00

https://www.eventbrite.co.uk/e/money-mattersfor-parentscarers-of-children-with-additional-needs-westmids-tickets-114476550444

Helping your child sleep Wednesday, 16 September 2020 19:30–21:30

https://www.eventbrite.co.uk/e/contact-online-workshop-helping-your-child-sleep-west-midlands-tickets-114479453126

Encouraging positive behaviour Thursday, 17 September 2020 10:00am–12:00pm https://www.eventbrite.co.uk/e/encouraging-positive-behaviour-in-children-west-midlands-tickets-115294691526

Wellbeing for parents/carers of children with additional needs Tuesday, 22 September 2020 12:00–14:00 https://www.eventbrite.co.uk/e/wellbeing-for-parentscarers-of-children-with-additional-needs-west-mids-tickets-114480081004

Money matters Wednuesday, 23 September 2020 19:30–21:30

https://www.eventbrite.co.uk/e/money-mattersfor-parentscarers-of-children-with-additional-needs-westmids-tickets-114480361844

Helping your child sleep Thursday, 24 September 2020 10:00am–12:00pm https://www.eventbrite.co.uk/e/contact-online-workshop-helping-your-child-sleep-west-midlands-tickets-115295481890

Wellbeing for parents/carers of children with additional needs Tuesday, 29 September 2020 10:00am–12:00pm https://www.eventbrite.co.uk/e/wellbeing-for-parentscarers-of-children-with-additional-needs-west-mids-tickets-115296049588

Wellbeing for parents/carers of children with additional needs Wednesday, 30 September 2020 19:30am–21:30pm https://www.eventbrite.co.uk/e/wellbeing-for-parentscarers-of-children-with-additional-needs-west-mids-tickets-114480696846







Did your baby spend time in a neonatal unit?



We are developing new content for www.Justonenorfolk.nhs.uk and want to hear about your experiences.

Please join us online to talk with other parents and help us to develop new resources for Norfolk families.

The session will be friendly and informal.

Tuesday 25th August at 11am or 7pm

Join us by using this link: bit.ly/norfolkmeet10

To find out more contact Michelle on 07833524216 or email michelle.walker6@nhs.net

Justone Norfolk.nhs.uk

Carers' views needed

Norfolk County Council are trying to help the Norfolk tourism industry recover following lockdown. They would really like some carers to help with this.





They are creating a project called EXPERIENCE to promote the new autumn/winter visitor experience. You can find out more about EXPERIENCE at https://www.norfolk.gov.uk/what-we-do-and-how-we-work/campaigns/experience-norfolk-sustainably.

Traditionally, Norfolk tourism has been centred on peak-season and mass-market locations, such as school-holiday beach visits to Great Yarmouth (great fun!). However, travellers are increasingly seeking encounters in which they experience a sense of adventure and discovery; for example, by immersing themselves in alternative cultures and inspirational arts, sampling local foods, exploring landscapes, investigating heritage, or discovering wildlife. This demand for 'experiential tourism' is the inspiration for EXPERIENCE. The project will create and promote unique and authentic individual activities, alongside exciting themed itineraries, in a high-profile marketing campaign that will extend the tourist season and bring money into local economies year round.

They are aiming to ensure that the tourist packages and associated cultural/artistic links are as accessible as possible. As the project is due to be completed by March 2023 it is in the very early stages, with the opportunity to embed accessibility for all into the whole process.

The project aims to find out what all Norfolk residents think would make good tourist destinations and they would particularly value your feedback as a carer, with all your knowledge and your experience, including accessibility issues.

For more information or to express an interest, please contact Patricia Day, Heritage Project, Officer, Environment Team, Community and Environment Services. Tel: 01603 217605 or via email at patricia.day@norfolk.gov.uk

Remember...

We are always keen to hear from you about the services you are receiving or would like to receive, so that we can inform decisionmakers about what families really need.

- You can contact our Membership Secretary Kate on 07950 302937 or at membership@familyvoice.org.uk
- Or write to us at Family Voice Norfolk, PO Box 1290, Long Stratton, Norwich NR15 2HD.

Or you can contact us via:

www.familyvoice.org.uk



FamilyVoiceNorfolk



<u>familyvoicenfk</u>

- Or join our Family Voice Members Chat Room on Facebook at https://www.facebook.com/groups/674209366743395/about/
- Look out, too, for our Family Voice Let's talk... sessions, which are held on Zoom.



Healthwatch Norfolk reveals what people said about information, care and support during lockdown



Healthwatch Norfolk has released the findings of its survey examining people's experience of accessing information, care and support during the COVID-19 pandemic.

133 carers, 175 people with a disability and 211 people who have been shielding were among the respondents, who shared their views between April and the start of July.

The patient voice organisation asked people to share their opinions on a range of issues, including accessing emergency and routine care, dealing with new digital systems, and obtaining important information to stay safe and informed during the pandemic.

The experience of vulnerable and 'shielding' people

The rapid multi-agency response from the NHS, local authorities, public health, and the voluntary sector is estimated to have helped over 41,000 clinically vulnerable – or 'shielding' – people in Norfolk.

Outreach programmes designed to identify and support vulnerable people with offers of emergency food parcels, prescription delivery services and emergency financial aid were coordinated locally via the Norfolk Resilience Forum, alongside efforts made nationally by central government.

Public agencies have been lauded for their reaction to the crisis by many, especially considering the government's shielding criteria has changed at different stages throughout the pandemic. However, some people told Healthwatch about being contacted too late, or not being identified at all by any support mechanisms. ...

People also highlighted the importance of being contacted in order to avoid feeling isolated, especially those who are shielding and unpaid carers – of which there are estimated to be almost 95,000 in Norfolk. A significant response rate from carers prompted Healthwatch to produce a supplementary report to draw attention to the issues faced by carers, who have a statutory right to receive support from local authorities under the Care Act 2014.

Of respondents who have been shielding and received practical support during self-isolation, 58% said they have relied on friends and family at some point, often alongside other services. 26% of people in this category also said neighbours have helped them and 39% of people have used local councils, who continue to be a major source of support through local Help Hubs.

GPs and pharmacists were also mentioned by respondents, and 24% have accessed practical support through charities or voluntary organisations, who have been crucial in linking disadvantaged groups with key information and support.

Access to clear and consistent information emerged as a prominent theme throughout the report, and while most people (69%) feel they have received all the information they need, the report highlights that not everyone is satisfied.

Some people told Healthwatch that "consistency in the information has been lacking", "guidelines are vague and contradicting" and that "mixed messages make it difficult to know who to trust".



Healthwatch Norfolk, which has previously raised concerns about interpretation services for deaf and hard-of-hearing people with NHS England & Improvement, also received feedback about information not always being easily available in accessible formats, including easy read, BSL, large text or braille. Similarly, increased reliance on phone consultations during the pandemic has been an issue for British Sign Language users trying to access GP appointments.

Accessing care during the pandemic

Restrictions on face-to-face consultations have led many providers, including hospitals, mental health services and GPs, to introduce new remote and online appointment systems. Respondents reported a mixed experience with using such systems, which are set to play an increasingly large role in the way healthcare is delivered after the pandemic.

Innovation in remote access to treatment has arguably been the largest unintended benefit to emerge from the COVID-19 outbreak, and of respondents who have had a remote GP consultation, 70% noted being satisfied with the experience.

Some positive experiences were also reported in mental health services, where platforms such as Kooth, Just One Norfolk's 'Chat Health' and NSFT's 24/7 helpline have all been adopted locally.

However, according to many respondents, mental health services, alongside dentistry, were still reported to be the most difficult forms of support to access.

Mental
health and social care over
the phone ... were both excellent
and exceeded my hopes.

NSFT have been well organised, even warning me prior to lockdown, Skype calls & appts & even review with 3 involved all excellent. **CAMHS**

... hard to get hold of and don't return calls or emails. Not providing any counselling over the phone just a quick check in and gone.

Adequate provision of dentistry continues to remain a top priority for Healthwatch, whose Chief Executive, Alex Stewart, spoke last week of how capacity in Norfolk's dental sector could "cause issues down the line" – especially for those not registered with a dentist already.

One member of the public in need of dental care during lockdown told Healthwatch, "There is no access to dental care for my 7-year-old who has now had tooth ache for 2 weeks. The only advice I have been given is to give her calpol", with another stating, "I cannot access urgent dental care despite being in pain for over two weeks due to a broken tooth/filling".

On the other hand, the county's GPs, hospitals and pharmacies generally received warm feedback from respondents. People told Healthwatch they were either "satisfied" or "very satisfied" most frequently with pharmacies (75% overall), followed by remote GP

appointments (70%) and in person GP appointments (66%). 64% of patients said they were either "satisfied" or "very satisfied" with hospital outpatient appointments.

Healthwatch also reports that while completing the survey, many respondents chose to thank and praise health and social care staff. The organisation acknowledges the unprecedented challenges faced by those delivering care, as Chief Executive Alex Stewart said:

"The last few months have seen a huge collaborative effort from health and social care providers across the county, in the face of challenges we have never seen in our lifetimes. The results of our survey show that lots of people are happy with the care they have received and grateful to the staff. However, there is evidently still lots of work to be done.

"Now, the challenge for the system as a whole is to make sure that we learn from the experience of both patients and professionals, making sure we continue with the good practice we have seen to make NHS and social care systems efficient and effective for everyone. This is where patient feedback and the role of local Healthwatch organisations is so vital.

Mr Stewart continued:

"Many people in Norfolk will feel the long-term impact of COVID-19, whether through the exacerbation of mental or physical ill-health, or even simply the loss of confidence to engage with their communities and services around them. We should use the skills and innovations that have developed to ensure that people most in need receive responsive support, whilst not forgetting that we have a duty to ensure care is equitable to everyone."

Healthwatch Norfolk's full report, including an easy read version, is available on their website alongside the additional carers report at https://healthwatch-pr-info-care-support-during-lockdown/.

"Thought
paramedics did
not have enough
equipment no
face shields"

"Young nurse who took ECG did not wear mask initially saying she wasn't at risk - but I was from her. She then put on a mask. Another nurse told me he would not be wearing a mask to talk me through results as not appropriate! No open windows to promote micro droplets dispersion."

"Care agencies not briefed well enough so carers no idea & ppe provided quite late on. I had to insist on hand washing on entry & had carers arguing that they didn't need to as had gloves"

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"[My carer] has not been given the proper PPE to protect herself and us from possible transmission [...] We have reduced our care visits to once a week as a result."



."The staff weren't wearing gloves and the consultant shook my hand at the QEH."

Learning Disabilities Partnership Board

There will be more about the development of this board in the next newsletter, but in the meantime, visit https://www.norfolk.gov.uk/care-support-and-health/support-for-living-independently/learning-disabilities-partnership-board to find out more.



Returning to school after a period of absence: questions to help the process for children, young people and their families



This leaflet, funded by the Department for Education and developed by families as part of NHS England's Ask Listen Do project, is intended to help build partnerships between families and schools. The intention is to equip families with questions to ask of schools to make the return to school from a period of absence as successful as possible. The questions can be used by families and by young people to support self-advocacy.

Although we have received this since the summer holidays began, there may still be questions that you will find useful in the next few weeks.

You can download the whole leaflet at https://www.sendgateway.org.uk/whole-school-send/find-wss-resources.html but we have listed some of the key questions below.

- How can we, as the family, share with you our knowledge about what is needed and what will work most effectively?
- How will children/young people be involved in shaping their own return and evaluating the extent to which it is successful and sustainable?
- How does the school support its staff in order to secure a successful return to school for children/young people?
- How will the school ensure that both families and children/young people know who to contact in order to raise any concerns?
- What services or expertise can the school access with regards to supporting the emotional wellbeing of children/young people both prior to and following their return to school?
- Where necessary, how will blended learning, accommodating both on-site and home education, be facilitated in order to meet the educational, social and emotional requirements of children/young people?
- How will the school ensure that a flexible approach is woven into the return to school and how will it be monitored in order to ensure that adjustments are made proactively in order to reduce the risk of placement breakdown?

- Where necessary, how will children/young people be supported to have a programme of variable attendance, and how will they and their families be involved in making decisions regarding what is required?
- What support will be provided for peer groups associated with the child/ young person as part of the planning and preparation for a return to school?
- How does the school evaluate what has worked well previously, or has not worked well, in order to inform effective practice and support the successful return to school?
- How will assessment be used in order to ensure that work is pitched at the correct developmental level following a period of sustained absence?
- How do you evaluate your policies, including those for behaviour, in order to support a successful return to school and how are any reasonable adjustments to those policies decided?
- How will you determine what reasonable adjustments need to be made to facilitate a successful return of children/young people with a disability to school?
- Has the school assessed the EHCP, where the child/young person has one, in order to ensure that the entitlements set out within it are available upon their return?

More libraries reopening

Norfolk Library and Information Service has reopened a further eight locations with safety measures in place at each site.

The locations are:

Monday 17 August

Attleborough Library

Aylsham Library

Costessey Library

Cromer Library

Dersingham Library

Long Stratton Library

Wells Library

Tuesday 18 August

Plumstead Road Library

This will take the total number of libraries open in Norfolk to 28 with plans in place to reopen the remaining sites in the coming weeks. Open library access remains unavailable across the library service and opening times have been changed accordingly.



SEND Family Roadshows

These Local Offer events were held last year at various places around the county, specially for parent carers with children or young people with special educational needs and/or disability. Family Voice Norfolk and other services took part.



This year the events will continue online so that representatives of the Local Offer can have regular conversations with parents and carers about:

- actions that will be taken to address the three serious weaknesses identified by the Ofsted/CQC Area SEND Inspection
- progress on the SEND and Alternative Provision (AP) Transformation Programme
- priorities that have been written into Norfolk's refreshed Area SEND Strategy.

Everyone who books a ticket for this Zoom event will receive the agenda and joining instructions nearer the date.

Planned dates are:

- Friday 25 September 2020, 10:30am-1:00pm via Zoom
- Wednesday 25 November 2020, 10:30am-1:00pm via Zoom
- Wednesday 27 January 2021, 10:30am-1:00pm via Zoom
- Wednesday 17 March 2021, 10:30–1:00pm via Zoom
- Wednesday 5 May 2021, 10:30–1:00pm (TBC Pensthorpe Nature Reserve or Zoom)

Find out more at https://www.norfolk.gov.uk/children-and-families/send-local-offer/about-the-local-offer/news-views-and-reviews/views/get-involved/send-family-roadshows

We hope to see you there!



bild



A helpline for families during Covid-19

Everyone knows it helps to talk to someone who understands our situation, and family and friends will always be our first choice. However, sometimes our children's behaviour means it helps to talk to someone who is hearing it for the first time, and who has experience and expertise with similar situations.



"It's nice to know there's someone there to support you"

Bild's qualified and experienced Positive Behaviour Support (PBS) consultants can provide targeted practical suggestions and strategies to help get through this next phase through PBS approaches. They will be providing phone support, both 1:1 and in small groups and family members can book an initial half hour call.

About Bild

At Bild we have been championing the human rights of people with disabilities since 1971. We work to understand people's needs and improve their quality of life. Our approach applies a rigorous evidence base, broad expertise and long-standing experience to find and enable both short and long-term solutions that bring about lasting change

About PBS

The overall aim of PBS is to improve the quality of a person's life and that of the people around them. It is especially appropriate when caring for people whose behaviour is challenging.

There will be a number of appointment slots for calls each day, typically between 10am and 3pm, but evening slots can be provided. Slots will be booked through Eventbrite. To book a free call, go to

https://www.eventbrite.co.uk/e/pbs-helpline-by-bild-registration-110952231110
The helpline has been funded by the Department of Health & Social Care.

Norfolk Assistance Scheme (NAS)

There are many people in our community who are vulnerable, and even more so during the coronavirus outbreak. Please be reassured that the Norfolk Assistance Scheme can help you get the ongoing support you need. Due to the coronavirus situation, a coordinated emergency relief response has been developed for Norfolk people in crisis.

Urgent help with food, cash or household items

The Norfolk Assistance Scheme can help by providing emergency cash or food due to the coronavirus situation. The scheme can also help provide essential household items such as white goods and beds. Please note that during this time of self-isolation these items may be delivered over the threshold or on the doorstep – advisors will discuss this with you. Please tell them in advance if you are unwell.

Urgent help with shopping, medication and other tasks

If you have no one to assist you, the Norfolk Assistance Scheme will arrange a delivery of food and refer you to the Covid-19 Community Response Team, who will work alongside Adult Social Services to refer you to a voluntary organisation to help you with tasks like getting shopping, picking up prescription medication, and dog-walking. Also, welfare check calls (by telephone or on the doorstep) can be requested.

Urgent help with gas and electricity costs

You may be able to get help with fuel costs through the Norfolk Assistance Scheme. Also contact your fuel supplier straight away if you're behind with payments of your gas or electricity bills. See Citizens Advice for help if you're on a pre-payment meter, have run out of credit and need gas or electricity urgently.

Am I eligible?

You must be a Norfolk resident aged 16 or over to apply for the Norfolk Assistance Scheme and you'll be asked a set of questions to check if you're eligible. You may be eligible if you:

- Receive or have applied for an income-related benefit (including those who are selfemployed or have recently been laid off work)
- Have ceased working and are awaiting salary payment through the government scheme
- Have dependent children
- Have a disability or mental health problem
- Are fleeing domestic violence
- Need help to remain in the community
- Are part of a planned resettlement scheme

How to apply

You can find out more at https://www.norfolk.gov.uk/care-support-and-health/support-for-living-independently/money-and-benefits/norfolk-assistance-scheme However, requests for emergency cash or food should be made via phone on 01603 223392 (option 5). You may be asked for evidence to support your application such as bank statements, payslips, UC journal entries and any other evidence NAS needs.



Norfolk SEND Partnership IASS training for parent carers

Norfolk SEND Partnership is looking to offer some free training sessions for parent carers but would like your input to help to make sure it is covering the topics you want to know about and offering the training when it suits you. The team has created a short survey to gather parent/carer views and would be very grateful if you could complete it.



Go to https://www.norfolksendpartnershipiass.org.uk/info-for-parents-carers/parentcarertraining/ to visit the website and complete the survey.

The survey closes 30 September 2020.

Statutory timescales for Education, Health and Care needs assessment and plan processes

The Department for Education/NHS England and NHS Improvement have confirmed that the Government has decided that the temporary changes to the law on the timescales for EHC needs assessment and plan processes will expire as planned on 25 September. The families of those affected by this should be informed by their EHCP Coordinator or educational setting.

Any cases where the coronavirus exception is being used to extend the timescale will need to be completed before the regulations expire and the timescales revert to the usual statutory deadline (e.g. 6 weeks for needs assessments, 6 weeks for the provision of information or advice and 20 weeks for issue of a final plan).

Local authorities, health bodies and other partners who play a part in these processes will need to consider how best to ensure timely progress over cases where the exception has been applied, identify the risks of any cases becoming overdue and do their best to prevent this happening. They are urged to communicate fully with individual families and to engage with their Parent Carer Forum [that's Family Voice Norfolk!] if there are implications for families generally in Norfolk.



Summer 2020 Family Learning Pack

The aim of this pack is to ensure children are able to continue to learn through fun experiences during the summer and as they transition back to school. You may have already received it from your educational setting. The activities in the pack will require differing levels of adult supervision. You can download it at https://www.schools.norfolk.gov.uk/search?searchFor=Summer%202020%20 Family%20Learning%20Pack



Learning for parent carers about county lines

We are including this information for two reasons: because young people with learning disabilities or difficulty in assessing whether friendships are genuine may be particularly vulnerable, and because many young people have sessions about these issues at school or college and parents may wish to understand what they have been told.

St Giles

SOS+ Programme

Gangs and County Lines Parents session on Zoom

By the end of this session, attendees should be able to:

- Understand the meaning of the term, county lines;
- Outline the methods used to groom, recruit and exploit young people;
- Gain an awareness of the push and pull factors that contribute to a young person becoming vulnerable and susceptible to county lines involvement;
- List the risks and consequences of county lines involvement;

- Recognise key signs and indicators that young people are being exploited or at risk of county lines involvement;
- Understand the perspective of either a survivor or perpetrator after hearing from an expert witness, including a brief overview of how girls are used;
- Facilitate a safe place within the household to encourage healthy conversations

Please join our <u>FREE</u> online sessions for Parents and carers

Our gangs & county lines parents' session consists of speakers utilising their lived experience within the criminal justice system to unpack and explore the realities and consequences of county lines, gang involvement, and serious youth violence.

Perspectives from previous perpetrators and runners/ transporters, combined with relevant case studies, aid audiences in gaining an authentic and credible understanding of this complex and cross cutting issue.

The session will help parents and carers to identify signs and triggers that a child/young person might be involved in county lines and gain an understanding of how to appropriately respond to such indicators.

CONTACT SOS+

E: sosplusadmin@stgilestrust.org.uk

T: 020 7708 8047

All other information: www.stgilestrust.org.uk

SOS+ Webinars click date to open linl Webinars are 60 minutes long including a Q&A session

1st September 2020 5:00pm

8th September 2020 5:00pm

17th September 2020 5:00pm

St Giles

Turning a past into a future

St Giles is a registered charity No 801355.
St Giles Head office, 64-68 Camberwell Church St, London, SE5 8JB.
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Roffell Morfels

What's online for families

Summer 2020

Monday

12pm Storytime 4pm Book Group

Tuesday

10am Bounce & Rhyme 11am Just a Cuppa: Babies & Toddlers edition

Wednesday

12pm Storytime 4:30pm Brick Building Club(alternate weeks)

Thursday

10am SRC Book Recommendations

Friday

9:30am School Readiness 12pm Story & Activity Time



All online sessions available at facebook.com/NorfolkLibrariesForFamilies except Just a Cuppa: B&T Edition.
Please email libraries.iconnect@norfolk.gov.uk to register your interest for this session

Bounce & Rhyme also available at youtube.com/NorfolkLibraries





Morfolk Libraries for Families

Just a Cuppa: **Babies and Toddlers Edition**

Join us on Zoom after our Tuesday Bounce & Rhyme Time for a special Just a Cuppa session!

The sessions are open to anyone who look after young children but are especially useful for those with babies.

Chat with other parents/carers from the comfort of home, some weeks we will have special guest speakers dropping in to chat about relevant children's services!

> To register your interest, please email libraries.iconnect@norfolk.gov.uk







Letter from Helen Whately MP, Minister of State for Care, and Vicky Ford MP, Parliamentary Under-Secretary of State for Children and Families

On 21 July, Helen Whately MP, Minister of Stare for Care, and Vicky Ford MP, Parliamentary Under-Secretary of State for Children and Families, sent an open letter to 'children and young people with SEND, their families and those who support them'.

You can view the whole letter at https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/20200721 DfE DHSC joint ministerial letter.pdf but the following extracts are the main points. Red text is our own editorial highlighting of significant information.

We want to express our sincere thanks for the key role that you have all played in the nation's response to dealing with the coronavirus (COVID-19) pandemic. It has been our overarching aim to ensure that children and young people with SEND continue to receive education and support throughout this time, but we recognise that this is likely to have been delivered differently than normal.

We want to update you on the actions that need to be taken to ensure that all pupils return to their schools from September, and respond to some of the concerns and questions that you have raised.

We recognise that some children with SEND will have additional health and behavioural vulnerabilities and may have been advised to shield in the early stages of the pandemic, and so a return to a more normal life might feel a big step. We want to assure you that we recognise this challenge and we are doing everything we can to support a safe return.

Below we:

- explain the importance of all pupils returning to school from September
- signpost our guidance to help educational settings prepare for the full return of pupils
- address the key concerns that have been shared with us about all pupils returning.

Learning lessons from the pandemic

Good practice has emerged as result of our response to the pandemic, which we are committed to building on as we move to the next phase of our response. For example, we understand from key stakeholders that there has been an improvement in collaboration between education and health care services in many areas. We will seek to identify and share this best practice where we can.

Full return to schools from September

We start from a belief that all children and young people should return to school full time to receive face-to-face education and support. This is particularly important for those with SEND. We recognise your concerns but we are clear that the benefits of being back in the classroom far outweigh the very low risk of contracting the virus, and schools can take action to reduce that risk even further.

From September, children and young people with SEND should continue to receive the therapeutic and other specialist interventions they would receive ordinarily. We are



adopting this approach because the scientific advice indicates that the prevalence of COVID-19 has decreased, the NHS Test and Trace system is up and running, and we are clear about the measures that need to be in place to create safer environments within schools.

Any child may need support in adjusting as they become accustomed to life back in school. Some pupils no longer required to shield but who generally remain under the care of a specialist health professional may need to discuss their care with their health professional before returning to school. More generally, where a pupil is unable to attend their setting because they are complying with clinical or public health advice, we expect settings to be able to immediately offer them access to remote education. We know that some of you are concerned that the level of transmission is not yet low enough or that children and young people will not be able to adhere to protective measures that are put in place. We can reassure you that we have not taken this decision lightly, and it is based on the latest available evidence. The latest advice from the Scientific Advisory Group for Emergencies (SAGE) shows that children are at a lower risk than adults, and are no more likely to transmit the disease.

All staff, children, young people and their families will continue to have access to testing if they develop COVID-19 symptoms, and your school will be provided with a small number of easy to use home testing kits forthose who might not otherwise receive one. If an individual tests positive, schools will receive direct support and advice from their local Public Heath England health protection team.

Guidance for educational settings

To support the full opening of schools, we have published a suite of guidance outlining the steps that educational settings need to take to ensure that children and young people [with] SEND return to full-time provision from September:

- Guidance for full opening: special schools and other specialist settings
- Actions for early years and childcare providers during the coronavirus (COVID-19) outbreak
- Guidance for full opening schools
- What FE colleges and providers will need to do from the start of the 2020 autumn term

Our starting point is that staff working day in, day out with children, young people with SEND and their families are best-placed to understand individual needs and the adjustments that need to be made before the full return in September.

Physical environment for those working with SEND children and young people
Our return to school guidance sets out a 'system of controls' to help reduce the risk of
transmission. We know that for those working with SEND children and young people,
maintaining physical distance – including by forming 'bubbles' – can be more difficult, because
staff come into close contact with those pupils or students. Schools should work through the
system of controls, and put in place the most appropriate measures for their circumstances,
without compromising the quality of teaching or care.

Helping children and young people prepare for their return to school

To ensure that children and young people receive the support they need to return to school, unless the evidence changes, we will not be issuing further national notices to modify the duty on local authorities and health commissioning bodies to secure or arrange the special



educational and health care provision set out in a child or young person's education, health and care (EHC) plan. Our focus will increasingly be on supporting local authorities, health bodies and schools as they work towards full provision being restored for all children and young people with EHC plans. We are calling on local services to prioritise support to children and young people with SEND so that they are able to access their usual therapies and other help they need to be in school.

We have also introduced a catch up package worth £1 billion including a 'Catch-Up Premium' worth a total of £650m to support schools to make up for lost teaching time. This funding could be used for specific support such as intervention programmes, extra teaching capacity, Speech and Language Therapists, Educational Psychologists, and access to technology or summer schools.

Although headteachers will decide how this premium is spent, according to the needs of their pupils, our expectation is that this funding will be spent on additional activities required to support children to catch-up. The Education Endowment Foundation has published <u>National Tutoring Programme Guidance</u> on effective interventions to support schools.

Alongside this, we have announced a new £350m National Tutoring Programme for disadvantaged pupils. This will increase access to high-quality tuition for disadvantaged and vulnerable children and young people, helping to accelerate their academic progress and tackling the attainment gap between them and their peers.

In addition, we have announced that out of school settings providing childcare, short break or respite services will be able to open from 1 July and into the summer holiday. We know that access to these services has been especially challenging over the past few months, and that this has had a significant impact on many families.

We updated <u>Protective measures for out-of-school settings during the coronavirus (COVID-19)</u> <u>outbreak</u> and <u>Coronavirus (COVID-19)</u>: <u>guidance for children's social care services</u> to make clear that <u>respite provision for children</u>, <u>young people with SEND and their families should be prioritised now that services have re-opened</u>, particularly over the summer holidays to help prepare for the return to school.

Local authorities will continue working with their short break providers in order to ensure they operate safely. It is important there is maximum flexibility to enable children to access services once again.

The Council for Disabled Children has worked with providers to produce <u>Short Break Learning Examples</u>. These case studies are examples of the effective ways services they are operating safely, and opening more widely, so that children, young people and their families can access vital support with confidence.

Transport to and from school

We recognise the importance of transport for children and young people with SEND and that their individual care needs, the type of vehicles and journeys may make it harder to reduce mixing and implement other protective measures. We are asking all settings with SEND children and young people to work closely with their local authority and their transport providers to implement measures that best reflect your particular circumstances, after undertaking a risk assessment.



Ofsted and CQC to support local areas to prioritise and meet the needs of children and young people with SEND

Ofsted announced in July that visits to local areas in autumn will focus on offering support to strengthen special educational needs and/or disabilities (SEND) systems as England begins to recover from the COVID-19 pandemic.

Ofsted and the Care Quality Commission (CQC) have been commissioned by the Department for Education and the Department of Health and Social Care to support local areas to improve their SEND systems. They will work in collaboration with local areas to understand the experiences of children and young people with SEND and their families during the pandemic, and to support local areas to prioritise and meet their needs. The visits will not replace the current SEND area inspections and Ofsted and CQC will return to SEND inspections when it is right to do so.

Ofsted has also published a report that evaluates the framework for inspecting local areas' SEND services. The full report can be found at https://www.gov.uk/government/publications/an-evaluation-of-the-framework-for-inspecting-local-areas-special-educational-needs-andor-disabilities-services

Key findings include:

- The inspections allow Ofsted to collect good evidence on how well areas identify children and young people with SEND and assess and meet their needs
- Joint working between inspectorates allows Ofsted and CQC to get a holistic picture of education and health provision, though there is a need for a greater emphasis on social care in future inspections
- Inspectors felt confident that the framework allows them to meet the aims of the inspection
- Inspections are a force for improving outcomes for children and young people with SEND.

Her Majesty's Chief Inspector, Amanda Spielman said:

There is no doubt that children and young people with SEND and their families have been affected significantly by the COVID-19 pandemic. Although many hard-working professionals and organisations have responded admirably by finding innovative ways to support children and families, we must not lose sight of the wide-ranging disruption to essential support and services still faced by many.

In Norfolk, work is underway to address the 'significant weaknesses' identified in the SEND Local Area Inspection carried out by Ofsted/CQC in March this year. A 'written statement of action' to Ofsted is required early in September.

Representatives of Family Voice Norfolk, alongside other parent groups and professionals from education, social care and health services, have been involved in many meetings over the summer to ensure that parent carer views are heard and taken into account. Simultaneously, work has been ongoing to give parent carer input in the recovery programme for COVID-19 and in the annual revision of the Norfolk Area Special Educational Needs and/or Disability (SEND) Strategy.

ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment.

The ReSPECT process creates a personalised recommendation for a person's clinical care in emergency situations where they are not able to make decisions or express their wishes.



The plan is created through conversations between the person and their health professionals. It is recorded on a purple paper form called the 'ReSPECT Form' that stays with the person.

The form should be available immediately to health professionals called to help in an emergency, whether the person is at home or being cared for elsewhere. Professionals such as ambulance crews, out-of-hours doctors, care home staff and hospital staff will be better able to make quick decisions about how best to help if they can see a ReSPECT form in an emergency.

ReSPECT is for anyone of any age. Although this is something people may think and talk about if they have a serious health condition or know that they are nearing the end of their life, in fact it is a conversation that we shouldn't be afraid to have with family, friends and/or professionals at any time. COVID-19 has brought home to many of us how uncertain life can be and that there is some comfort in having done everything we can to make things clear for those trying to help us or for family needing to guess our wishes when we cannot tell them.

It is not just about resuscitation wishes. It's a chance to talk about the kinds of treatment that might be available and what they would entail. You can find out more about ReSPECT on the national website at https://www.resus.org.uk/respect, or by watching a film of Dr Caroline Barry, Consultant in Palliative Care at the Norfolk and Norwich University Hospital, talking about the importance of ReSPECT for helping to make sure patients get the care they would choose (https://www.youtube.com/watch?v=g9NBBpi8818&feature=youtu.be).

How you can help

Norfolk and Waveney Clinical Commissioning Group (CCG) would like to design a public marketing campaign to let everyone know about ReSPECT in Norfolk and Waveney. You can help by completing a questionnaire on the above website or at https://www.smartsurvey.co.uk/s/ReSPECT_2020/ so that they can find out:

- what people know about ReSPECT already
- what are the most helpful messages to spread understanding about the importance of planning for emergency care and treatment
- what are the best ways to share those messages with people in Norfolk and Waveney.

Your answers will be used to create communications about ReSPECT for Norfolk and Waveney. You do not have to give your name or contact details. But there is an opportunity at the end of the survey to volunteer for a focus group if you would like to do so.

Please send any queries relating to ReSPECT to nwccq.contactus@nhs.net.

"I posted on here as I know everyone gets it." Comment on our Family Voice Members Chat Room. Have you joined? Go to https://www.facebook.com/groups/674209366743395/about/



Family Voice AGM 28 July 2020

This year our AGM was held via Zoom. It felt odd not to meet in person but we were delighted to welcome parent carers, professionals and representatives of SENsational Families to our annual meeting. We were also pleased that Mrunal Sisodia, Co-Chair of the National Network of Parent Carer Forums (NNPCF) and Julie Singleton from Contact, the charity that administers the grant we receive as a parent carer forum from the Department for Education, were able to join us.



Mrunal Sisodia

Mrunal gave an opening speech, reminding us that Family Voice Norfolk was one of the pioneers in parent carer forums and should be proud of its achievements: sending representatives to 299 meetings last year and producing a newsletter that feeds back news of our acitivities to parent carers as well as sharing other information of interest.

Mrunal talked about 2019–20 being a year of two halves. 2019 saw the government's SEND funding review that resulted in an extra £780m for SEND, a review of the Ofsted school inspection framework and the NHS Long Term Plan. All of these had been urged and contributed to by the NNPCF. Then there was the general election, which meant that work on these projects stopped. Just as work was beginning again on these important initiatives, COVID-19 arrived and put a stop to further developments again.

That doesn't mean that work for NNPCF and parent carer forums has stopped. Far from it. NNPCF has been working with government departments during lockdown and has helped make changes to national policy, including:

- working with NICE (the National Institute for Health and Care Excellence), early on in lockdown, on the clinical frailty scale. Within a week, parent carers had worked to ensure that children and young people with SEND had the same rights as others;
- allowing children and young people with SEND to be able to leave the house during lockdown as and when required for exercise, fresh air and a change of environment;
- working on the school guidance document to ensure that this allows for reasonable adjustments for children and young people with SEND;
- working to secure that the £100m catch-up fund includes SEN catch-up, speech and language therapy, occupational therapy and education psychologists.

Mrunal finished his speech by saying that parent carer forums were more important than ever, during these times of COVID-19, essential to represent the views of families to service-providers so that provision meets the needs of families.

Julie Singleton, Contact's Parent Carer Participation Advisor for the East and South East of England, then spoke about the grant money that Family Voice receives via Contact.

Tracey Sismey, the Chair of Family Voice Norfolk, explained that, due to the unprecedented demands of COVID-19, it had been agreed to keep the members of the Family Voice steering group the same for the next six months. It was proposed and agreed that Anita Evans, who has been a co-opted member, should be elected as a full voting member of the steering group.

You can read the full AGM documents and reports on our website at https://www.familyvoice.org.uk/articles-reports/agms/