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Family Voice Norfolk – staying alert in so many ways...

After almost three months of extraordinary times, it looks as though navigating the easing of lockdown may be even trickier than getting used to it in the first place. For Family Voice, as for many families, change presents both new opportunities and many new challenges. In this newsletter, find out about:

- the outcome of the **SEND Local Area Ofsted/CQC inspection** – what happens next?
- how **Family Voice is still working** to advise and inform decision-makers in education, health and social care
- how we are **operating flexibly** in these changing times and our plans to future-proof our work
- how Family Voice Norfolk makes sure **your views are heard nationally**, at the heart of government
- a new way to **share your views** with us about back to school and other issues
- how **other families are managing** in these tricky times
- services that may **help you and your family**



Ofsted/CQC Local Area SEND inspection

The first week of March, when Ofsted/CQC inspectors came to Norfolk and inspected the provision of SEND support and services, feels a long time ago now. So much has happened since then.

However, the response from Ofsted has now been received in the form of a letter to Sara Tough, Executive Director of Children's Services, and Melanie Craig, Accountable Officer, NHS Norfolk and Waveney Clinical Commissioning Group.

"The content of the report will not surprise parent carers in Norfolk."

Tracey Sismey, Chair of Family Voice Norfolk

You can read the full text of the letter on our website at <https://www.familyvoice.org.uk/wp-content/uploads/2020/06/Norfolk-County-Council-10125218-final.pdf> and you will find Norfolk County Council's response at www.norfolk.gov.uk/news.

Ofsted and CQC determined that Norfolk should prepare a written statement of action to address areas in need of improvement. There will be a reinspection in a year's time to check on progress.

The first thing we would like to say as Family Voice Norfolk is a big **thank you** to all the families who shared their experiences with the inspectors, both by email and in person at meetings in educational settings and at the Professional Development Centre in Norwich.

It is quite clear from the report that the inspectors heard you – and, indeed, they heard *us* when we also represented the views of families at further meetings and in a series of reports and documents we supplied.

The inspectors highlighted three main areas of 'significant concern'. In their own words:

● **Too many EHC plans and annual reviews are not completed in a timely manner and are of poor quality.** This limits the scope and impact of joint commissioning, including the timeliness of services to meet speech, language and communication needs; for children and young people with social, emotional, mental health needs; and for those with ASD.

● **Plans and provision for young people as they move into adulthood are not sufficient to meet their needs.** There is a lack of support for the young people to become active, independent citizens in the community, in a way that matches their needs and aspirations.

● **Too often, communication with parents and carers is poor.** Co-production with children, young people and their families is too limited. These weaknesses particularly affect, but are not exclusive to, children and young people with SEND who do not have an EHC plan. Families are not sufficiently informed about what help is available to them and what the area is doing to address the weaknesses in provision and services for children and young people. Many families are understandably frustrated and anxious and believe that no one is listening to them.

In addition to these key areas, the inspectors highlighted many other findings, both positive and negative. You can read them all in the full letter. Many of them may directly relate to what your own family has experienced.

What are the next steps?

We know – because we have contributed to it – that in the past two years a great deal of work has gone on to address what is not working for our families in Norfolk. But as the Ofsted letter underlines, it can take families far too long to see the results of planned change in their own lives and outcomes.

We know that the local authority has already started work on the issues of concern.



In one way, the COVID-19 pandemic has made work on these issues more difficult, but if it has shown us one thing it is that when the need and the will is there, change to priorities, services and ways of working can happen enormously quickly and effectively. The Ofsted/CQC letter, although disheartening in one way, is a real opportunity to accelerate improvements to assessments and services for our families. Ofsted themselves will be engaged with Norfolk and so will we as the parent carer forum.

A large part of our work often takes place behind closed doors. There's nothing sinister about that. While work is in progress, ideas adapt and evolve – it's not helpful or sensible to comment in detail on what we are doing to represent your voices.

Although we aim always to be professional, we do not hesitate to challenge strongly the local authority, health and voluntary organisations about their plans and services.

We were pleased to see that Ofsted recognised this. The letter comments about our work and that of other parent carer groups in several places:

Organisations such as Family Voice and the SEND information advice and support service (SENDIASS) have not shied away from confronting area leaders about the needs of families and the problems they face.

and

Family Voice is tenacious in the challenge that it offers to area leaders. Many very positive changes are the result of Family Voice championing the rights of families.

We are pleased, too, that the letter recognises that we at Family Voice Norfolk value the roles of other parent carer groups and regularly work with them to encourage change. The theme of our Conference only a few weeks ago was of how much more powerful our voices can be if we all work together. Family Voice Norfolk is not a

support group or primarily an information-giving organisation. Our work takes place around tables, in front of screens, and often buried in mounds of paperwork. But we value any organisation that supports families more directly, even if that is not our remit. As the Ofsted letter says:

Some parents incorrectly believe that Family Voice is not being proactive in challenging leaders about the inadequacies in provision. They feel that other groups are more likely to champion their cause more effectively. Some parents and carers do not know how these groups work together to champion the rights of children and young people with SEND through partnership working with the local authority and the CCGs.

There is a challenge to all of us who work for families with SEND to ensure that as many as possible hear about our work and can gain from it.

Opportunities for parents and carers to come together and support one another are increasing, most notably as a result of Family Voice, SENSational Families and SEN Network. However, many parents and carers do not know that these groups exist, and so do not get their views heard.

So please, we will do everything we can to continue our work even more vigorously, but we need your help:

Tell us about what matters to you and how services affect your family.

We want to hear the good things – so they can be increased – as well as the not-so-good that need to be changed. And...

Make sure your friends with children with SEND also know how important it is to speak up. With our help they can do so easily and anonymously.

Your voices really matter. We are developing new ways for you to engage with us and with each other. Read on in this newsletter to find out more about these.



How Family Voice Norfolk is working during the pandemic



In these difficult times, more than ever, we need to make sure that the voices of families with children and young people with special educational needs and/or disability (SEND) are heard by those who plan and deliver services.

Last year, one of the ways we did that was by sending **representatives to over 400 meetings** and workstreams with the local authority, health and voluntary services, putting forward the needs and experiences of families like ours.

In order to be sure that we were giving a true picture of families' views, our **ambassadors** attended meetings, ran stalls at events and met up with parent carers wherever they could. We held **Family Voice, Family Chat sessions**, where professionals gave information and families told us about their experiences. We also ran several **'5-Minute Focus' surveys**, asking for your views on subjects such as Short Breaks, SEND transport and childcare. And last (just before lockdown) but by no means least, we held our annual **Family Voice Conference**, where parents and professionals could get together and exchange information and experiences.

You can read about our activities and all the reports that we have shared with you and with decision-makers on our website at www.familyvoice.org.uk.

Operating in lockdown

Obviously, since the current situation began, we have not been able to attend face-to-face meetings or events, but we have not stopped representing your views. All our representatives, ambassadors and steering group members are also parent carers of children and young people from 0 to 25 with SEND. For many that has meant, as it has for you, having children at home and many new challenges to family life. Some have been shielding because of their own or relatives' health needs. Many of us have found that this time has given us an increased awareness of both our children's strengths and their challenges. But the work of Family Voice as Norfolk's parent carer forum has gone on.

As for most people, our screen time has increased hugely. So many emails and interactions have taken place that last month we suffered serious problems with the capacity of our provider to give us the service we need. This affected our ability to send out large mailings,



such as newsletters, and means that some emails have not been getting through. We have now found a new provider and we will shortly be migrating – we hope seamlessly – to a better situation. Do check your spam and junk folders for our mailings until then.

In the meantime, we have continued with our work, often via Zoom or Teams meetings online:

- Increasingly, meetings and workstreams that paused at the beginning of lockdown are now up and running again, and we are participating fully in these.
- Since our family lives are not always predictable, we are designating two representatives to attend most meetings, so that if family, health or technical issues mean that one is unable to focus on a Zoom meeting, the other can take over.
- Like many of the service providers and planners we work with, we are finding that not having to travel to meetings is saving time and money and frequently enabling us to achieve more. We miss the immediacy of face-to-face meetings, but we are getting used to the new etiquette and possibilities of online discussion.
- In the current fast-moving situation, good communication is key. We are increasing the frequency of our online internal steering group and representatives meetings – meeting more briefly but more often – to ensure that we can be as responsive as possible to changing conditions.
- As services and needs change daily, some of our external meetings, such as those with Adult Social Care, have also become more frequent. We ‘meet’ at least fortnightly to share information and pass on important requests and comments about how families are experiencing new systems and adapted services. Some issues have been dealt with really quickly as a result of this.
- Our Facebook page at <https://www.facebook.com/FamilyVoiceNorfolk/> continues to share information and opportunities of value to families with SEND.
- This newsletter is back with a bumper edition!
- Finally, we have created two new ways for you to keep in touch with us and make sure your views are heard – a new closed Facebook Family Voice Members Chat Room and our Let’s talk... online sessions. see pages 6 and 7 for more information about these.

As always, hearing your views and experiences is absolutely key to what we do. Please keep in touch in any way that works for you. See page 22 for a reminder of all possible methods.

Children and young people who self-harm– pilot project

Children and young people in central Norfolk who need care or are at risk of needing care from NNUH’s Emergency Department due to repeated self-harm will be able to access support through a pilot project, which is designed to enhance crisis care. NSFT’s Children and Young People’s Crisis Assessment and Intensive Support Team will continue to provide immediate help before referring suitable service-users to a new pathway called RUSH (Rapid response pathway – United to reduce Self-Harm). Within 48 working hours, service users will be offered eight sessions of social or psychological interventions or advice by practitioners from MAP (Mancroft Advice Project). The pilot pathway will initially cater for up to 125 people aged between 11 and 18. If you would like to hear more, join the Microsoft Teams Live Event on 10 June 2020 11:00–12:00 by clicking <https://bit.ly/2BK1ZVP> to join the live event.



Family Voice Let's talk...

Our Family Voice Family Chat sessions around the county have proved a useful way of exchanging information about key issues that concern families with SEND. At our sessions on SEN Support and Education, Health and Care Plans, and Transport, we asked professionals to join us to share information and answer your questions. We (and they) also learnt a lot from what you told us about how services worked or did not work for your families.

We can't meet like that at the moment and those sessions – booking venues etc. – take time to organise. These days we need to be able to share quickly and respond quickly to what is happening.

Family Voice Let's talk... is a new way of sharing views and information. We have already held our first two sessions, on **Let's talk... about back to school**.

The online format no longer feels strange and we will develop different ways of running these sessions depending on the topic being discussed.

As usual with our participation events, we have written a report about the issues you shared with us – always being careful to anonymise any comments. This will be available to read on our website very shortly and has already been useful in informing what we say in meetings with the local authority. That's especially important as we are not in a 'one size fits all' situation now. Some families are happy for their children to return to school; some are very anxious; some do not feel it is appropriate for their circumstances at the moment.

We intend to follow up on this work later in June, but in the meantime, here are the key points we took from the sessions:

- All children are different and the proposed flexible arrangement, of parents being able



to choose whether their child can return to school or not, allows parent carers to make those individual decisions.

- Some families found that the support they received from school by various means has been better, more individual and usefully differentiated, than their child has ever experienced before.
- Children and young people (CYP) with learning difficulties often need frequent and consistent practice to gain skills. Many will need refresher courses on, for example, travel training, even if things return to 'normal'.
- Siblings of children with SEND have sometimes found lockdown additionally difficult and the whole family may be in real need, individually, of breaks or respite.
- Transitions are a concern for families approaching key moves. While some services and settings have been doing excellent work, others have not addressed this at all, and indeed, are themselves probably unsure about what will happen.
- There has been a huge variety in the frequency and quality with which schools have engaged with families. We heard of excellent and very poor communication.
- For some CYP, being at home has brought increased happiness and calmness as the stresses of school life, travelling (sometimes for a long time each day) and school behavioural expectations do not have to be dealt with.
- All families welcomed the possibility of increased flexibility – education for individuals, not an imaginary 'average' child.



Family Voice Members Chat Room

Our Facebook page at <https://www.facebook.com/FamilyVoiceNorfolk/> is ideal for sharing news but it is a public page and not suitable for sharing family information or concerns. We have begun a closed group called **Family Voice Members Chat Room** where full members of Family Voice can share freely in a safe environment. What you tell us helps

us to speak powerfully in meetings with the local authority, health and voluntary services, but we would never, ever pass on anything that could identify you or your family.

To join the closed group, go to <https://www.facebook.com/groups/674209366743395/about/>. If you are not yet a full member – membership is **free** to anyone with a child aged between 0 and 25 with SEND – fill in the form on our website at www.familyvoice.org.uk.

Family Voice steering group – no change...

At this time of year we have usually recently held our Annual General Meeting, elected new steering group members and assigned roles. We have decided that, although we will hold a virtual AGM, we will keep the steering group as it is until the COVID-19 situation is no longer affecting everything we do. It is unfair to expect new steering group members to take on challenging roles in the current climate and, indeed, it would be difficult for us to outline what exactly we would expect someone to do. We are simply having to be flexible.

You can view current steering group members and our administrators on our website at <https://www.familyvoice.org.uk/about-us/how-we-work/>

But new representatives, please get in touch...

COVID-19 and the ever-changing landscape for our children and young people with SEND means that we are busier than ever. As the local authority works towards recovery plans and addresses the issues raised in the Ofsted/CQC local area SEND inspection, we will be working to ensure that families' views are taken into account. New representatives are mentored and begin by shadowing experienced reps – which at the moment means observing in Zoom and Teams meetings and attending online Reps meetings. The wider the range of family experiences we have among our representatives, the better. If you have ever considered taking on a role with us, please do get in touch with Kate at membership@familyvoice.org.uk

Representatives are paid for the time they spend in meetings (you can view our remuneration policies on our website at www.familyvoice.org.uk) and can also claim travel expenses – but at the moment, there's no travel involved at all! All our steering group members and reps are themselves parent carers of a child or young person with SEND, so we absolutely understand that family life comes first and would never expect you to take on more than is right for you.

And new members are *always* welcome!

If you are the parent carer of a child or young person aged 0–25 with SEND you can become a full member of Family Voice Norfolk by filling in the form on our website. Membership is **FREE** and enables us to keep in touch with you more easily. It also means that you can join our closed Facebook group: Family Voice Members Chat Room, where you can share views with other parent carers in a safe environment. See above for more details.



We are proud of our logo!

So you may wonder why you do not see it more often on the work we have been involved in. As with all our policies and ways of working, we publish our views transparently on our website, but at this time we thought it might be useful to share them with you below. This is the statement we share with anyone who asks to use our logo on their publications.

Family Voice Norfolk works with Norfolk County Council, health services and the voluntary sector to ensure that the experiences and views of families with a child or young person with special educational needs and disabilities (SEND) are taken into account when services are being planned, created, delivered or discussed.

As you know, the range of needs of families with SEND is huge – no two families are the same. Views are wide, too, and sometimes conflicting. We do our best to represent the majority and to take into account the wider picture. That would include, for example, an understanding that resources for SEND are not unlimited, improvement can sometimes take a long time, and national and local policies change.

As a result, although we hope that our input always makes a positive difference for families, it is rarely the case that we feel that a piece of work is perfect in every way and delivers all that we would wish. The general public does not see how we have been involved and what influence we have had. There is always room for something better. Nor do we usually have any control at all over the way in which work we have been involved in is used, publicised, referenced or connected to other initiatives.

*We are transparent about the fact that although some of our funding comes from the Department for Education, some also comes from Norfolk County Council and the Clinical Commissioning Group in Norfolk. We are aware that some people question whether we can be truly challenging because of this. We aim to work **with** the LA and other services but not **for** them.*

We ask, as a matter of courtesy, that third parties ask us before including our name in lists of those who have contributed to a piece of work, but we are open about work we have done, so this is usually not a problem. However, use of our logo implies a greater degree of involvement and looks like an endorsement. For all the reasons above, we decided some time ago that rather than making frequent difficult decisions about when it is appropriate for our logo to be used, we would be very clear that it is only used on documents that we ourselves have created and, occasionally, to publicise events where we have a specific part to play.

Our reason for being clear about this is the same as our reason for everything we do: we want as many parent carers as possible to share their experiences with us, so that we can represent them where decisions are made and improve services for their families.

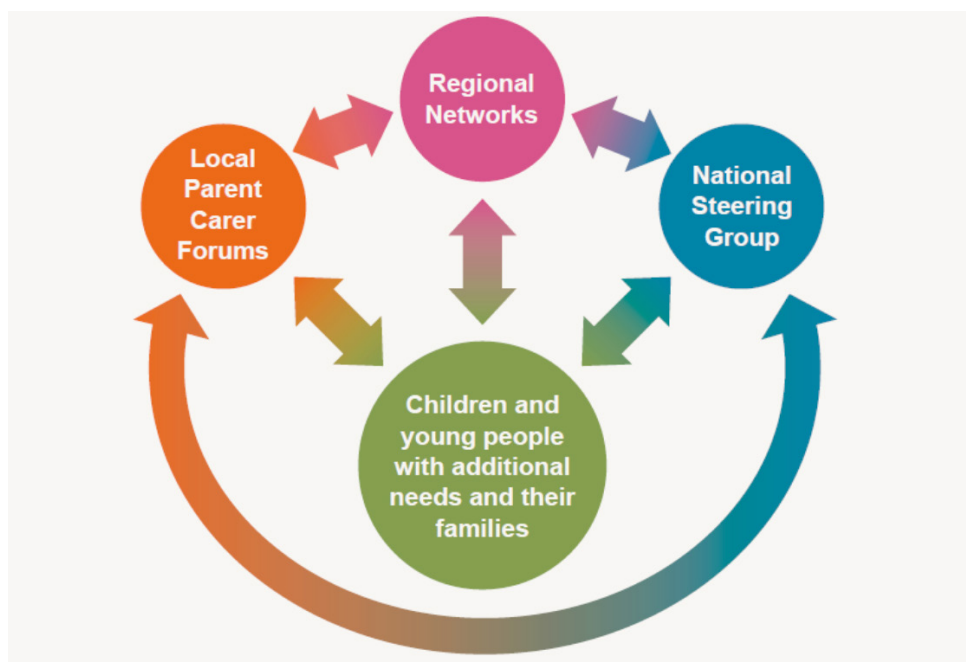


Family Voice and the bigger picture

We often report on how we represent the views and experiences of families with children and young people with SEND in Norfolk. We report less often about the fact that we represent your views in two directions – to Norfolk planners, decision-makers and services, to ensure that resources are used in ways that will be most helpful to families, but also to regional and national bodies so that central government takes the views of real families from Norfolk into account when developing policies.



The second role is a key part of our identity as a parent carer forum. Information about parent carer forums is available on our website at <https://www.familyvoice.org.uk/what-are-parent-carer-forums/>. As the parent carer forum for Norfolk, we are part of the Eastern Region of Parent Carer Forums (ERPCF) and attend meetings regularly to exchange information and views with other parent carer forums in the region. Via the ERPCF but also directly we have access to the National Network of Parent Carer Forums (NNPCF). This body feeds the views of up to 152 parent carer forums in England to the heart of government, meeting regularly with ministers and officials. We consider this to be a key part of our work and it is helpful that local policymakers know that we have this access.



As you can see from the above diagram, information is shared between all levels of the parent carer forum networks. You too can find out more about the NNPCF at <http://www.nnpcf.org.uk>. Under 'Current activities' you can see the very many national initiatives, boards and enquiries that include NNPCF representatives. Family Voice Norfolk feeds the experiences of Norfolk families to the NNPCF so that your voices are heard nationally as well as locally.

On 11 May, for example, NNPCF co-chairs Tina Emery and Mrunal Sisodia met with Children and Families Minister Vicky Ford to discuss the government's ongoing response to the COVID-19 pandemic. Mrunal was previously co-chair of the Eastern Region of Parent Carer Forums, so we at Family Voice Norfolk have known him personally for many years. He is



passionate about representing families and is himself the father of a child with SEND, as all PCF members are.

The Minister was very aware of all the work that the parent carer forums have been doing in response to the pandemic and thanked them for their input and contribution. The NNPCF shared and continues to update a list of issues from parent carer forums across England, to which Family Voice Norfolk has contributed. You can read the updated list at <http://www.nnpcf.org.uk/working-list-of-nnpcf-thoughts-on-school-re-opening/>. What you tell us goes directly to national decision-makers. It really is true that 'together we are stronger'.

The contact with government is continuous. On 29 May 2020, the NNPCF and other organisations wrote an open letter to Vicky Ford MP, Parliamentary Under Secretary of State for Children and Families, outlining concerns regarding the situation of children and young people with SEND during and after the COVID-19 pandemic:

Whilst the Coronavirus Act and accompanying DfE guidance relating to SEND were introduced with the aim of supporting local authorities to respond to the current crisis, we have significant concerns about the disproportionate impact on this group of children, who already experience poorer outcomes than their peers. In particular, we are concerned about the modification of Section 42 of the Children and Families Act and the variability in the interpretation of 'reasonable endeavours'. Whilst we acknowledge and recognise the incredible efforts that many services and professionals have gone to in order to keep support going in many areas over the last few months, parents are reporting that some local authorities are making little or no attempt to engage with them to agree what provision in their child's Education, Health and Care Plan will continue to be made and how and when this will happen. We are also concerned about reports regarding the number of therapeutic interventions not being provided, and the potential impact of this on children's physical and mental health and wellbeing both now and in the longer term. Given that we expect an imminent announcement regarding the extension of the current notice (which ends on May 31st), we would like to ask how your Department is monitoring these processes, what provision is being made; how the measures have affected children with SEND and what evidence will inform any subsequent decisions should there be any further extensions of the current notice.

In addition, we ask you to ensure that there is no further extension of the amended arrangements to vary timescales in The Special Educational Needs and Disability (Coronavirus) (Amendment) Regulations 2020, beyond the current end date of 25th September, as we are particularly concerned that those children and young people who are waiting for a plan to be issued or amended are not disadvantaged any further. The issue of when/how children and young people will return to school/settings also remains problematic. We are concerned that although discussions are currently focusing on the search for a specific date, significant issues affecting children and young people with SEND are being overlooked:

- *How children with SEND can be expected to return to school/settings without the support outlined in their EHC plans, or through SEN Support, which enables them to access learning*
- *What children and young people with SEND will need to supplement provision in an EHC plan, or on SEN support, during and after lockdown*
- *How preparations for transition into new educational settings and phases of education will be undertaken, with a focus on accessibility/reasonable adjustments, to restore a sense of belonging and welcome*



- *How to restore wellbeing during reintegration, to support a positive return to current schools/ settings, and avoid the issues that can lead to disruptive behaviour and exclusions.*

The plan for a return to school/settings needs to focus on promoting wellbeing, securing missing therapies and individual planning for all pupils with SEND. This approach needs to be applied consistently across the country. In many ways the restrictions faced within the current pandemic have simply magnified the pre-existing inequalities experienced by children and young people with SEND over many years.

*Over the past 6 months many of our organisations have met and fed into the government's SEND Review, which set out to both examine the effectiveness of the current system, and provide changes and solutions to improve the efficiency, effectiveness and sustainability of this system. It is not clear where the SEND Review currently lies, but we feel strongly that it needs to come out of cold storage urgently and be adapted to fit the current extraordinary circumstances, and the ongoing legacy of these days – like so many other areas in our lives, it can no longer be 'business as usual'. We would very much welcome the opportunity to support the ongoing work of this Review, as **we feel that nothing short of an overarching re-design of many aspects of the system is enough to address the gross inequalities in educational entitlement faced by many children and young people with SEND.** The SEND Review and the Care Review urgently need to focus on the design of health and social care provision to support children, young people and their families in their local community.*

You may already have read Vicky Ford's open letter of 30 May 'To all children and young people with special educational needs and disabilities (SEND), their parents/carers and families, and others who support them'. You can read it in full at <http://www.nnpcf.org.uk/wp-content/uploads/2020/06/Minister-Fords-open-letter-to-SEND-sector-schools-opening.pdf>

If you do not have time to read it in full, it also contains links to guidance for teachers, school leaders, carers, parents and students that may be of interest and can be found at <https://www.gov.uk/coronavirus/education-and-childcare>

Also of interest is additional money being put into the Family Fund (£37.3 million in 2020–21). The Family Fund provides grants to families on low incomes who have children with disabilities or severe medical conditions, and this funding includes £10 million which has been allocated to help families in response to the Covid-19 pandemic. More details can be found at www.familyfund.org.uk



How we help Get involved News and events About us Contact us Donate

Apply for a grant
If you're raising a disabled or seriously ill child, and need support with essential items, we can help
[Read more](#)



New guidance on Education, Health and Care Needs Assessments and Plans (EHCPs)

The government has announced temporary changes to the law on Education, Health and Care (EHC) needs assessments and plans. This is to give local authorities, health commissioning bodies, education settings and others who contribute to these processes more flexibility in responding to the demands placed on them by coronavirus.

The Secretary of State for Education issued a notice under the Coronavirus Act 2020 to modify section 42 of the Children and Families Act 2014 – duty to secure special educational provision and health care provision in accordance with EHC plan. The modification to Section 42 means that: the duty on local authorities or health commissioning bodies to secure or arrange the provision is temporarily modified to: **a duty to use ‘reasonable endeavours’ to do so.**

There will also be changes in the Special Educational Needs and Disabilities Regulations, temporarily amending the statutory timescales for various EHC needs assessment and plan processes. The Special Educational Needs and Disability (Coronavirus) (Amendment) Regulations 2020 (the ‘Amendment Regulations’) temporarily amends four sets of Regulations that specify timescales that apply to local authorities, health commissioning bodies and others: mainly for various processes relating to EHC needs assessments and plans.

Minister Ford, Parliamentary Under Secretary of State for Children and Families, and Minister Whately, Parliamentary Under Secretary of State for Care, wrote a joint ministerial letter to children and young people with SEND and their parents and carers.

Minister Ford and Minister Whately note:

‘We know that as parents and others involved in the care of this vulnerable group, your primary concern is their health and wellbeing. As the Ministers for SEND and Care, we share those concerns and want to reassure you that these changes are temporary and all other requirements of the EHC process remain unchanged.’

Dame Christine Lenehan, Director of the Council for Disabled Children, said:

‘CDC supports the Government response to the virus but will be using all of our networks to ensure that children’s and families’ needs are still being met in the most reasonable way possible. We will also be supporting practitioners to develop innovative approaches. As soon as the virus is passed we will be working to ensure the measures are withdrawn and the full system entitlements are available. We will also be advocating for the next stage of SEND review consultation to begin.’

Norfolk’s statement about how the local authority is adapting to the current situation can be read on the SEND Local Offer website at <https://www.norfolk.gov.uk/children-and-families/send-local-offer/support-for-learning/education-health-and-care-ehc-plans/affect-of-coronavirus-on-ehc-plans>



Despite the current situation with COVID-19, Norfolk SEND Partnership Information, Advice and Support Service (SENDIASS) is still working and continuing to offer information, advice and support about special educational needs and disabilities. See their website at <https://www.norfolksendpartnershiass.org.uk> for more details and how to contact them.



This poem with illustrations was sent in by EP, a parent carer member.

Bank holiday Monday, Easter 2020 – Lockdown

It worked

Woken by the rant at 4am
"Shut up, Go away.... I'm not polite..."
The record is in a jam
And not a ray of hope or sunshine in sight.

My heart sank. Ignore it
She'll go back to sleep
No, please! "Shut up, Go away... I'm not polite..."
Two hours later I wanted to weep.

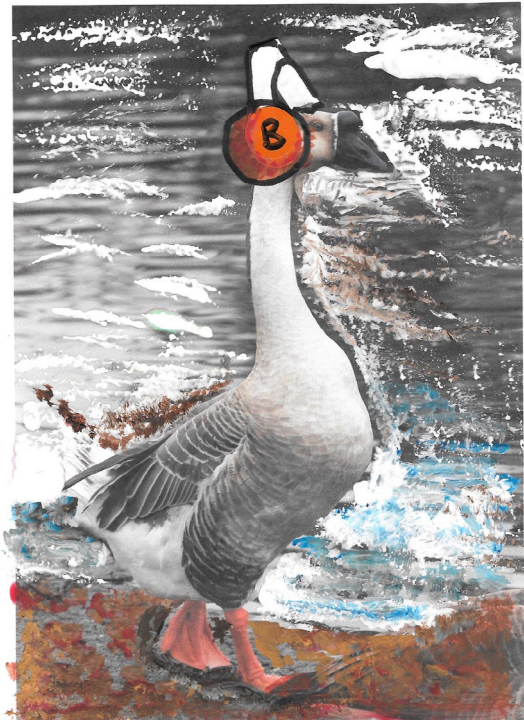
You can't weep – it needs action.
Joggers, trainers and a slug of coffee
And one teenage daughter with ASD and only a
fraction
Of understanding and cooperation, and no
empathy.
"Shut up, Go away... I'm not polite, polite, polite,
polite..."

I bundled her into the car
"Shut up, Go away... I'm not polite... GO
AWAAAYYY!"
It's loud, very loud, they heard near and far.
I drove on silent roads with a purpose in mind –
"Shut up, Go away... I'm not polite... Go away!
Go away! Go away!"
– To Whitlingham Broad, where we could find
space to walk and rant and walk and rant and
walk and..
"Shut up, Go away... I'm not polite."

"Shut up, Go away... I'm not polite..."
The pace was fast
She was angry and confused.
Benches and boats thundered past
We are not sitting down, I point blank refused.
"Shut up, Go away... I'm not polite..."
No runners,

No cyclists.
The dog walkers were absent too.
Thank God...
"Shut up, Go away... I'm not polite..."

Jam butties and juice, a feast for two
We sat on bench No.5 – (Jim's bench, he loved it
here.)
Because the Broad is vast and beautiful and Oh!
What a view.
"I'm a polite girl mummy, No thank you, No
Thank you, NO THANK YOU!"
We watched the geese
"Why do I get stuck?"
And listened to the peace.
I managed to find some chocolate in my bag
A small pleasure gratefully received
A burst of energy, so we won't flag.
And so indeed...



One more lap to tire her out
 "I get stuck mummy"
 We must sleep tonight without a doubt.
 Bench No.7 (Eileen's bench – she loved it too.)
 "I don't like things changing mummy"
 My heart lifted, relief overwhelmed me
 A short but gentle conversation
 Free for the moment, of meltdown and anxiety

We pressed on and finished our walk
 "Toddlers have little legs, why do they have
 little legs? Jenna has little legs"
 "Yes she's got little legs."
 She's back...
 2 laps of Whitlingham Broad
 5 miles on foot at speed
 2 benches
 Jam butties and juice
 Home by 9am
 Exhausted.



A family coping with ASD.

Staying active

The COVID-19 pandemic is having a huge impact on our lives and routines, and creating unprecedented financial hardships for the clubs and groups that 'normally' support us to be active.

Active Norfolk is providing information and resources to support people of all ages and abilities to be active at home, and to support the physical activity sector to weather the impact of the pandemic. Go to <https://www.activenorfolk.org/coronavirus-covid-19> where information is regularly updated.

active
norfolk




WE NEED YOU!

Does your child start school or move up to high school in September?





Come along join us and other parents to talk about this.

Share ideas and see what is available on the Just One Norfolk website to help you and your children to get ready for starting a new school

Use this link: bit.ly/norfolkmeet4 to download Microsoft Teams and join the group on

Friday 19th June 13:30pm

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



My Autism, Our Lives, Our Norfolk



The Norfolk Autism Partnership Board (NAPB) has formally launched 'My Autism, Our Lives, Our Norfolk', a five-year strategy that sets out the county's ambition to transform the support autistic people, their families and carers can access.

The NAPB is a collaboration between autistic people, their parents/carers, and voluntary and statutory organisations, working together to co-produce and implement a local autism strategy.

The strategy details nine priorities to be delivered over the next five years. It responds to what people have reported locally alongside guidance established nationally. The strategy also lays out the responsibilities of delivering the 'Think Autism' statutory guidance, as well as the priorities in the NHS Long Term Plan. 'My Autism, Our Lives, Our Norfolk,' has been created with the input of autistic people at every stage, alongside family carers, voluntary sector organisations and community groups.

The NAPB has the responsibility of overseeing the implementation of the strategy over the next five years, including reviewing plans each year to ensure they continue to reflect local and national priorities.

The launch also heralds the publication of a **questionnaire, to hear from autistic people and their carers about how life and the care and support they receive has changed during the COVID-19 pandemic.**

The NAPB would like to find out more about how children and adults with autism have coped with the coronavirus lockdown and what support and advice they need as the lockdown is eased. Most importantly, the Board is keen to hear about the impact on mental health, anxiety and behaviour, and what services have been helpful over this period. It is also key to find out what might help support people over the coming months. The information from this survey will help to make sure that autistic adults, children and their families in Norfolk get the help and support they need.

The closing date for the survey is **29 June 2020.**

www.norfolk.gov.uk/autismcovid19survey will take you to the NAPB web page, where you will be able to:

- download the strategy, both in full and as an Easy Read version
- find out more about the NAPB
- access the survey – click on the green bar at the top of the page
- read the NAPB's most recent newsletter and access other information
- find out more about how you too can be involved in the partnership.

Autistic people of all ages and their families can give their views and be part of the wider conversation by joining the partnership. You can read about this on the above link and fill in a form, or email autism@norfolk.gov.uk.





Are you 11-25 yrs old?

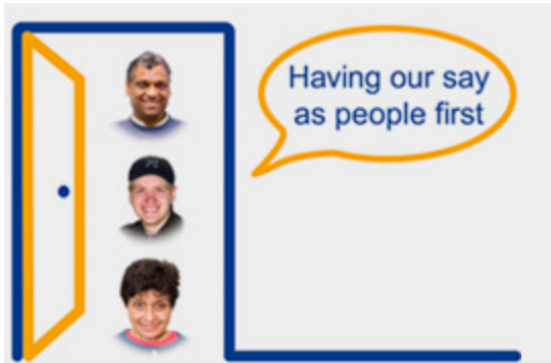
with Special educational needs or disabilities, and in education or training?

Have
your
say

CLICK HERE for more information
and to complete our short survey

www.norfolksendpartnershiass.org.uk 01603 704070





Opening Doors

Opening Doors is a user-led organisation for people with learning disabilities, which specialises in recognising people as individuals. Its mission is for all adults with learning disabilities in Norfolk to be confident individuals, controlling their own lives and making their own decisions, with support from people they trust.

On the Opening Doors website at <http://www.openingdoors.org.uk> you can find a regular easy-read newsletter about the COVID-19 pandemic, explaining terms being used in the news, how to keep safe and suggesting activities to do during lockdown.

You can also read about Opening Doors' other services and activities.



Online counselling for 11- to 25-year-olds

Kooth is a service from the Norfolk and Suffolk NHS Foundation Trust that offers 11- to 25-year-olds across Norfolk and Suffolk access to online counselling delivered by qualified counsellors 365 days a year, either on a drop-in basis or through bookable chat sessions. The website also gives young people the chance to benefit from peer support and a wide range of self-help materials, as well as contribute to moderated forums.

Visit www.kooth.com

Kooth is open 7 days a week, 365 days a year, from noon until 10pm weekdays and 6pm until 10pm on Saturdays and Sundays.

Kooth allows children and young people to provide each other with peer-to-peer support through moderated online discussion boards and the ability to contribute to self-help articles and content. Qualified counsellors are online seven days a week to provide online counselling through chat-based messaging via drop-in or booked sessions. Young people will also be able to track their mood with a goals tracker as well as note their thoughts in an online journal.

Young people can use Kooth to seek support or advice on any topic they wish, from managing their feelings during the pandemic or coping with exam stress or bullying to seeking help for an eating disorder, dealing with suicidal thoughts or handling sexual abuse.

For urgent help, call the 24/7 NSFT First Response Helpline on 0808 196 3494.



Due to the current situation with Coronavirus (COVID-19), we have had to make some changes to the way we work in the community. We want to ensure that the families, children and young people that really need our support can still access help.

From 1st June 2020, we have updated the services that the NHS has agreed are essential for families. In Norfolk these are:

Just one Number

0300 300 0123

The Just One Number team can help you by providing health advice about your baby, child or young person. Just call 0300 300 0123 with any health questions or concerns you may have.

Parentline 07520 631590

Text messaging advice service for Norfolk parents/carers of 0 - 19 year olds. Send a text and one of our team will text you back with advice.

Mon - Fri 8am -6pm
Sat 9am - 1pm

JustOneNorfolk.nhs.uk

Our digital platform which provides all sorts of advice, information and support for you, your baby, child and young person. It has advice on how to manage during the current coronavirus pandemic as well as links through to other services. You can also create an account so you can watch your confidence and knowledge improve as you learn more.

All information is free, clinically approved by the NHS and available 24/7.

Antenatal Visit

We will contact you to arrange a phone or video call with a health visitor after you are 28 weeks pregnant.



They will ask you about your feelings about the pregnancy, your health, and your unborn baby's health. This contact will enable us to get to know you and your family, and it is also a chance for you to ask any questions or to discuss any worries.

Pathway to Parenting (P2P)

A digital antenatal programme for parents to be.

It helps you think about the development of your unborn baby and the first few weeks after birth. It includes how things may change and some of the practical skills to care for your baby.



Search for 'P2P' on JustOneNorfolk.nhs.uk

New Birth Visit/ 6 - 8 Week Review



We will contact you to arrange a phone or video call with a health visitor between 10 - 14 days after your baby has been born and around 6 - 8 weeks old.

This is to find out how you are feeling and to discuss the health and wellbeing of your new baby and your family. The Health Visitor can support you with advice about caring for your baby, feeding, safe sleeping, crying, immunisations, and any other health issues.

3 - 4 Month and 6 - 9 Month Contacts

For now we will be contacting families when babies are between 3 - 4 months and 6 - 9 months old.

This is to remind families our services are still here if you need us and how to access further support if needed.



School Readiness

We have a lot of information on JustOneNorfolk to help you to prepare your child for school. Try the online 'Starting School' quiz. For now our staff will be contacting families whose children are due to start school in September 2020,



Starting High School

To support you we have information on JustOneNorfolk. We have created a quiz to work through that provides a fun way to explore with your child some of the new experiences they may face.

ChatHealth

Text messaging advice service for 11- 19 year olds. 9am - 5pm Mon to Fri

07480 635060

16-19 Health Passport

The app provides general health information and advice on a variety of topics for 16 - 19 year olds



Health Unlocked



Our online parent support forum, where families can talk and support each other by sharing their individual experiences.

HealthUnlocked.com/
one-norfolk-parents

All other services will pause until the NHS tells us we can start them again.

Norfolk Children and Young People's Services is provided by Cambridgeshire Community Services NHS Trust and commissioned by Norfolk County Council



Stay safe from scams

Sadly, although lockdown has helped to keep us safe from COVID-19, it has given an opportunity to scammers.

With many of us spending more time on-line, including children and vulnerable young people, and more of us at home to answer the phone, scammers have been inventive about how they operate.

It's worth reviewing your 'house rules' about answering the door and the phone and dealing with emails.

While no one wants young people to become more anxious than necessary, it is empowering for them to understand some common sense warning flags:

- if something sounds too good to be true, it probably is.
- it's okay to reject, refuse or ignore requests, or ask for more time to think about something. Genuine people will understand. Only criminals will try to rush or panic you into a decision.
- never click on a link in an email unless you are absolutely certain about where it has come from. If you are not sure, or this is a new contact, always check with a family member or carer.

- check with a family member or carer before accepting offers of help, however well meaning they sound. Again, genuine people will be fine with that. Anyone who tries to persuade you or rush you is probably a scammer or someone you can't rely on.
- we all want to feel and be safe. Don't pass on stories or information you have read online unless it is from a really reliable source. You might be scaring someone who doesn't have as much support and common sense as you do.

National Trading Standards have a scams team and lots of advice at <https://www.friendsagainstscams.org.uk> including a 20-minute online training video that will open your eyes to the many ways scammers can catch us unawares.



Carers' Covid Update

Norfolk and Suffolk NHS Foundation Trust (NSFT) is publishing a regular newsletter for carers with information about their services and other useful sources of support. You can find the current and past newsletters at <https://www.nsft.nhs.uk> under 'Find help' and 'Carer news'.

The Trust has also launched a **Q & A email address** specifically for carers to contact with their concerns. Emails sent to covid19q&a@nsft.nhs.uk will be responded to directly and some Frequently Asked Questions will be put together and published on the NSFT website.



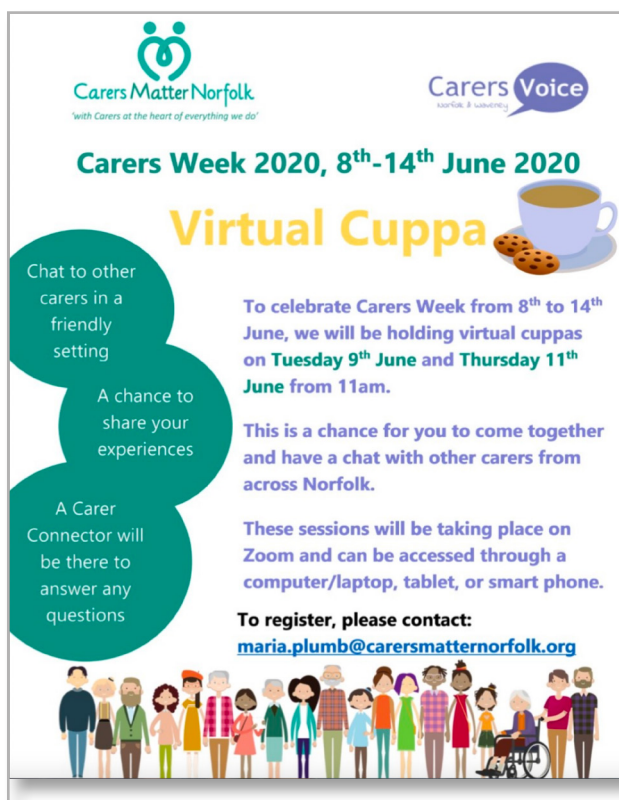
 Positively...  Respectfully...  Together...



Carers Week 8–14 June

This year, Carers Week activities are having to take place online, of course. Below is a timetable of what's going on for the rest of the week. If you would like to get involved but haven't got in touch with Carers Matter yet, please email Sophie.Little@carersmatternorfolk.org so that the Zoom links can be sent to you.

Carers Matter Norfolk are also holding 'Virtual Cuppas' on Tuesday 9th June and Thursday 11th June if you want to come together and chat with other carers from across Norfolk.



The graphic features the Carers Matter Norfolk logo (with the tagline 'With Carers at the heart of everything we do') and the Carers Voice logo (with the tagline 'Norfolk & Waveney'). The main title is 'Carers Week 2020, 8th-14th June 2020' followed by 'Virtual Cuppa' with an illustration of a cup of coffee and cookies. Three teal speech bubbles contain the following text: 'Chat to other carers in a friendly setting', 'A chance to share your experiences', and 'A Carer Connector will be there to answer any questions'. The central text reads: 'To celebrate Carers Week from 8th to 14th June, we will be holding virtual cuppas on Tuesday 9th June and Thursday 11th June from 11am. This is a chance for you to come together and have a chat with other carers from across Norfolk. These sessions will be taking place on Zoom and can be accessed through a computer/laptop, tablet, or smart phone. To register, please contact: maria.plumb@carersmatternorfolk.org'. At the bottom is an illustration of a diverse group of people, including one person in a wheelchair.

Wednesday, 10 June 2020

Origami

10.30am–10.50am

Beth Williams from Voluntary Norfolk (SOS BUS Manager) will be teaching you how to turn a piece of paper into a star and some storage for it!

Mindfulness drawing

10.50am–11.15am

Grace Hillard from Therapy Aid will be running a mindfulness drawing session to relax and find yourself in the present moment. You will need a piece of paper and two different coloured pens/pencils.

Mindfulness meditation exercises & guided relaxation

11.15am–11.45am

Adele Powell will be leading some mindfulness meditation exercises moving into a guided relaxation. You don't need anything to join in with this one!

Healthwatch update

11.45am–12pm

Healthwatch are interested on hearing your views as a carer on the services you have experienced during Covid-19. (See also page 21 of this newsletter.)

Friday, 12 June 2020

Prize Bingo

10.30am–11.00am

If you previously signed up to receive an activity pack from Carers Voice Norfolk & Waveney, you can enjoy three rounds of Bingo using the Bingo cards from the pack. The winner in each game is the first person to get a full house and will receive a prize!

Laughter yoga

11.00am–11.30am

Beverley Bishop from Therapy Aid will be holding a virtual laughter yoga session. Be prepared to laugh ... a lot!

Planting update

11.30am–11.40am

An update on the seeds planted at the start of the week.

Close of Carers Week events

11.40am–11.45am

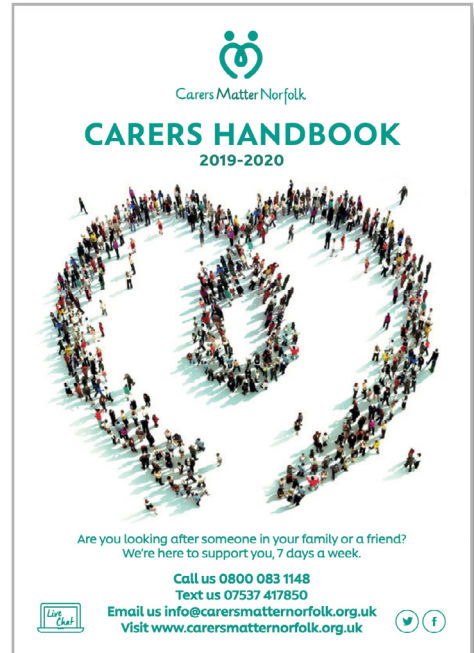


Carers Handbook 2019–2020

The latest edition of the Carers Handbook is still available to download on the Carers Matter Norfolk website at carersmatternorfolk.org.uk.

Printed copies of the handbook cannot be collected from libraries at the moment for obvious reasons, but if you need one, email info@carersmatternorfolk.org.uk and it may be possible to send you a copy.

The Carers Matter website also includes lots of information about support for carers, including what is available right now during the COVID-19 pandemic, your money, rights and wellbeing, and support for young carers.



healthwatch Norfolk needs your views...

Healthwatch Norfolk gathers people's views of health and social care services in the county and makes sure they are heard by the people in charge.

Commissioners and service providers have to listen to them. So, whether you have had a good or bad experience, your views can help to make changes to services in Norfolk.

Healthwatch's work covers all areas of health and social care. This includes GPs, hospitals, dentists, care homes, pharmacies, opticians and more.

Share your experience of accessing information, care and support during COVID-19.

Healthwatch Norfolk is working with local councils, hospitals and other service providers to help them understand the needs of their communities in these challenging times.

Tell them about your experience of accessing the right information, support and health and social care services by completing a **short survey**.

Whether you have had a positive or negative experience since the COVID-19 outbreak, it is important that you share your thoughts so that providers know what is working well and what could be improved.

You can find the survey on the Healthwatch Norfolk website at <https://healthwatchnorfolk.co.uk/hwn-covid-19-survey/> where you can also find an **easy read version of the survey** and see what other service users have said about their experience of services during this time.

Healthwatch is publishing an update on service-users' views every two weeks.

together we are stronger



Taking care of teeth...

At a time when many dentists are warning that they will be unable to open when restrictions lift (though do check with yours, especially if your need is urgent), there is advice from the NHS in Norfolk about toothcare at <https://www.justonenorfolk.nhs.uk/healthylifestyles/teeth-and-toothbrushing> including a section for children with additional needs.



Mental health support for children and young people

Many organisations have changed what they do as a result of COVID-19. Support for children and young people's mental health and emotional wellbeing has also changed.

You can find a number of sources of support at <https://www.justonenorfolk.nhs.uk/mentalhealth>

You don't need a referral, you can get in touch straight away for advice and support.

See also the article on page 17 of this newsletter about Kooth, a service for 11–25-year-olds.



The next newsletter will appear in July 2020. If there are issues that you would like to see covered, please email comms@familyvoice.org.uk or leave a message on 07535 895748.

Emotional Health

Remember...

At Family Voice we are always keen to hear from you about the services you are receiving or would like to receive, so that we can inform decision-makers about what families really need.

- You can contact our **Membership Secretary Kate** on 07950 302937 or at membership@familyvoice.org.uk

- Or you can contact us via:



www.familyvoice.org.uk



[FamilyVoiceNorfolk](https://www.facebook.com/FamilyVoiceNorfolk)



[familyvoicenfuk](https://twitter.com/familyvoicenfuk)

- And if you would like to share your views with other parent carers in a safe environment, you can join our **Family Voice Members Chat Room** on Facebook by going to <https://www.facebook.com/groups/674209366743395/about/>

- Look out, too, for our **Family Voice Let's talk...** sessions, which are held on Zoom, and where you can discuss your views and experiences about hot topics with other parent carers, and gain ideas and new perspectives on the issues faced by families like yours.

- And finally, if none of those works for you, we're very happy to receive letters or even postcards at Family Voice Norfolk, PO Box 1290, Long Stratton, Norwich NR15 2HD.

