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If there are issues you would like to see in future newsletters, contact [comms@familyvoice.org.uk](mailto:comms@familyvoice.org.uk) or leave a message on 07535 895748.

## New Blue Badge rules for 'invisible' disabilities now in force



From **30 August 2019** the rules about who is eligible for a Blue Badge for parking have changed to include those with 'invisible' disabilities such

as autism, learning disability or mental health conditions. Although people with non-physical disabilities have not been excluded from receiving a Blue Badge previously, the new criteria give clear and consistent guidelines on Blue Badge eligibility for the whole of England.

This follows a consultation in 2018, as a result of which eligibility is extended to people who:

- cannot undertake a journey without there being a risk of serious harm to their health

or safety or that of any other person (such as young children and adults with autism)

- cannot undertake a journey without it causing them very considerable psychological distress
- have very considerable difficulty when walking (both the physical act and experience of walking).

At the time of writing, the Norfolk County Council website was not showing the new criteria but it is a national change.

You can read more about it and the results of the consultation at <https://www.gov.uk/government/news/people-with-hidden-disabilities-to-benefit-from-blue-badges>



**Book now! Book now! Book now! Book now! Book now!**

Our first **Family Voice, Family Chat** sessions for this school year are only a couple of weeks away. They are an excellent chance to find out more about **SEN Support** and **Education, Health and Care Plans (EHCPs)** and to tell us about your experiences and concerns, as well as meeting other parent carers. Please email [events@familyvoice.org.uk](mailto:events@familyvoice.org.uk) to ensure you have a place at one of our five sessions around the county or call/text on 07535 895748.



**Are you the parent of a child or young person with special educational needs and/or disabilities (SEND)?**

Join us for coffee at an information and feedback session about

**SEN Support**  
**and Education, Health and Care Plans (EHCPs)**

We've invited Norfolk SEND Partnership Information, Advice and Support Service (**SENDIASS**) and a representative of the Local Offer to join us so you can:

- Find out more about SEN Support and EHCP assessments
- Tell us about your own experiences of support for your child with SEND
- Ask questions in a relaxed setting
- Share ideas with other parent carers



**Tuesday 17 September** 10.00am – 1.00pm  
Community Room, South Lynn Community Centre, 10 St. Michael's Road, **King's Lynn**, PE30 5HE

**Monday 23 September** 10.00am – 1.00pm  
The Suite, Dereham Football Club, Aldiss Park, Norwich Road, **Dereham**, NR20 3PX

**Tuesday 24 September** 10.00am – 1.00pm  
The Noble Hall, The Priory Centre, Priory Plain, **Great Yarmouth**, NR30 1NW

**Monday 30 September** 10.00am – 1.00pm  
The Colman Room, South Norfolk House, Cygnet Court, **Long Stratton**, NR15 2XE

**Wednesday 2 October** 10.00am – 1.00pm  
Main Hall, Aylsham Care Trust, St. Michael's Avenue, **Aylsham**, NR11 6YA

If you can come, please email us at [events@familyvoice.org.uk](mailto:events@familyvoice.org.uk) or call/text on 07535 895748.





## Norfolk Disability Pride 29 September 2019 The Forum, Norwich 10.00am–4.00pm

Following last year's successful event, this year will be an even bigger celebration of disabled people and the diversity of our Norfolk community.

It's a **free** event with something for everyone, including:

**activities** that highlight the skills and abilities of disabled people and challenge negative stereotypes.

**a marketplace** bringing together individuals, groups and businesses to engage with disabled people, opening up conversations and opportunities to develop inclusive services and activities.

**Family Voice Norfolk will be there!**

**music** from a wide range of performers, including Norfolk Singing Hands, the UEA Community Choir and the Black Dog Music Project.

You can find out about the day's events at <https://equallives.org.uk/get-involved/disability-pride/disability-pride-whats-happening-on-the-day/> or on Disability Pride's own website: <https://www.norfolkdisabilitypride.org.uk> made possible through the support of The Forum.

Disability Pride is being run in partnership with Equal Lives, The Forum, Norfolk County Council and the University of East Anglia.

## Looking for Dragons!

The Disability Real Action Group Of Norfolk (**DRAGON**) is made up of 11–25 year olds with a disability who enjoy being involved in:

- helping young people to access and be involved in their community services
- taking part in big decisions that affect the services young people use
- being a voice for people with disabilities
- reviewing leisure venues, clubs and other facilities
- helping people make friends and have lots of fun
- making real change happen.

They are looking for new members! If you are interested, get in touch with Sarah Harrison, DRAGON Project Lead, on 01603 627662 / 07795 576983 or [dragons.project@outlook.com](mailto:dragons.project@outlook.com)



## Save the date(s)

More information will be available shortly, but the Local Offer Roadshow is coming to a venue near you over the next few months:

- Friday 11 October (Holt)
- Friday 6 December (King's Lynn)
- Weds 12 February 2020 (Great Yarmouth)
- Weds 25 March (Thetford)
- Weds 20 May (Norwich)
- Tuesday 30 June (Fakenham)



## SEND e-Newsletter

If you don't already subscribe to Norfolk's **free** SEND e-Newsletter, or your former subscription has lapsed because you've changed your email address, you can easily make sure you receive it at [www.norfolk.gov.uk/send](http://www.norfolk.gov.uk/send) – the Local Offer website.

The newsletter is full of information about events and services in Norfolk that may be of interest to you and your family. It is produced as part of the Local Offer in co-production with Family Voice and other interested groups. If you have comments or would like to submit an article, you can contact the newsletter editors on [send@norfolk.gov.uk](mailto:send@norfolk.gov.uk)

The next edition of the e-Newsletter will be published in September.



## Family Voice Norfolk newsletter deadlines

The next edition of this Family Voice newsletter will be published at the end of September. If there are issues that you would like to see covered, please email [comms@familyvoice.org.uk](mailto:comms@familyvoice.org.uk) or leave a message on 07535 895748 before 24 September 2019.



## SEND e-Learning Course

This e-learning course has been designed to support the professional development of those who work, or are training, in the field of SEND. It gives learners a foundation knowledge and understanding of SEND for children and young people aged 0–25.

It is also a useful tool for **parent carers** and anyone interested in developing their knowledge and understanding of SEND.

The course includes assessments to demonstrate and reinforce learning, and there are links to further reading.

In response to comments from a Family Voice member, the course has already been improved as follows:

- You no longer have to tackle the whole course in one sitting. You can now access each module of the course individually. You will need to allow approximately two to three hours to complete the course in its entirety. Once all modules have been completed, the menu page will display this.
- The e-learning is not configured for mobile devices and is best viewed on a desktop computer or laptop but you can now download it as a pdf PowerPoint presentation (16.5 MB).

The course can be accessed on the Local Offer at [www.norfolk.gov.uk/send](http://www.norfolk.gov.uk/send) via the **Training, events and things to do** tab.





## More top tips from parent carers

Following our feature on tips from parent carers last month, a few more have been sent in. Do let us know if you have found something that works for you and you feel could help other families. *These have worked for other families, but of course make your own checks about financial and other advice – your family's needs may be quite different.*

- "For girls who wear pads for incontinence, Marks and Spencer and Next do modesty shorts up to the age of 16 which are ideal for keeping pads in place and concealing them. I struggled for ages to find decent knickers that were big enough for pads, and was spending a fortune on buying ones from Germany! These ones are much more affordable."
- "My daughter got into trouble with the bank by getting overdrawn when using contactless. I had assumed that, like taking money out at a cashpoint, the machine checked that you have the money in the account. Apparently not. However, most banks are able to put a 'zero overdraft' facility on the account so that the contactless will be like a cashpoint and refuse to pay if there is no money. We've done that and although there is sometimes disappointment, we don't get fined and I don't have to transfer more money than she needs to her account to get her into the black to withdraw money at a cashpoint."
- "Also on money, we tried to do online banking so that she could check before going out if she had the funds (avoiding the disappointment!) but she couldn't do the 'give the fifth, third and first digit of your password' thing in her head, only by writing it down, which defeats the object of being secure. Now, though, with the app on her phone, she can do it with a fingerprint. It's secure and there's a facility for me to add my fingerprint so that we can both check if necessary."
- "Always get a friend to help you fill in forms where you have to describe your child's difficulties, such as PIP or ESA or DLA. It's not that you can't do it yourself, but sometimes it takes someone else to give you 'permission' to describe the challenges of a bad day rather than the pride of a good one. I don't spend most of my time saying 'He can't do this or that', I try to be positive. But those forms need a different kind of truth if your child is to get the support s/he is entitled to."

It's never too early to save the date!

**Family Voice Norfolk Tenth Annual Conference**

**Saturday, 14 March 2020**

**John Innes Centre, Norwich NR4 7UH**



## Online survey updates ... and thanks!

Thank you to everyone who responded to our recent surveys. We had a huge response and have already begun to use the information you gave us (carefully anonymised) in meetings with the local authority and NHS, with the aim of improving services for families like yours.



Some of the experiences you shared with us were distressing to read and must have been upsetting for you to communicate as well, but these stories are so valuable when we are explaining the views of parent carers and how services affect their families. They remind decision-makers what it really means for us all when services are cut or not effectively delivered. Talking about the overall picture has its place, too, but real facts and figures and real experiences from real parent carers can change the whole atmosphere of a meeting and help us all to focus on what matters – our children and young people with special educational needs and/or disabilities (SEND) and the families who love and care for them.

Here is a quick update on recent surveys:

**SEND Funding survey** – although this survey was live for only five days, right at the end of term when families are frantically busy, we had a huge response from you. We have already written a report and shared it with

- the Department for Education (DfE), which was undertaking a national survey of professionals and families
- the National Network of Parent Carer Forums (NNPCF), of which Family Voice Norfolk is a member and via which we are able to ensure that our local issues are heard by government at a national level
- Norfolk County Council (NCC), including those working on the Norfolk Area SEND Strategy 2019–2022 (see page 8 of this newsletter).

The full report will be available on our website at [www.familyvoice.org.uk](http://www.familyvoice.org.uk) very shortly by following Articles and reports, then Survey results.

**Speech and Language Therapy (SaLT) services survey** – this is not the first time we have asked about SaLT experiences but you have given us lots of new information. It's not a very happy picture, with 60% of families who responded having waited for over six months for a service and 24% for over a year. **If you are one of those, please contact the service to ensure that you are still on the list.** The report is being written at the moment, ready to be presented to the Health Overview Scrutiny Committee (HOSC) in October.

**Childcare and Short Breaks survey** – this was a massive survey that aimed to glean a lot of information at once. Thank you if you had the stamina for this! Information on the childcare part has already been reported back to meetings attempting to address the difficulty families experience in finding this and the challenges this presents for parent carers seeking to return to employment. Further reports on Short Breaks are being prepared.

All of the above will be available to be viewed on our website as soon as possible.



## Pilot scheme for mental health support teams in schools for children and young people in Norfolk

The Norfolk and Waveney Sustainability and Transformation Partnership (STP) has successfully bid to pilot a new national scheme providing therapy and support to primary, secondary and special school children.

The STP is a partnership of NHS and county councils, working together to improve health and care for local people.

They will initially commission two pilots, in King's Lynn and North Norfolk, with each supporting children with mild to moderate mental health needs, across 40 schools.

Funded by the Department for Education and Department of Health, the teams will provide talking therapy and group support and consultation and supervision for staff.

This is part of Norfolk and Waveney STP's aim of transforming mental health and wellbeing services for children and young people, with a focus on earlier help and community-based support and enablement. It has published a new strategy to improve services and also a briefing note on the STP website at [www.norfolkandwaveneypartnership.org.uk](http://www.norfolkandwaveneypartnership.org.uk)

Sara Tough, Executive Director for Children's Services at Norfolk County Council and STP lead for children and young people, said: "We know that children's mental health can impact on every aspect of their lives – their education, relationships and physical health.

"That's why we want to transform services so that we can get help to children and young people earlier, in their schools and communities where they are comfortable and feel supported.

"These new mental health teams will be a huge asset in developing that approach, by not only providing direct support to children and young people but helping both parents and school staff to understand what is happening for their children and how they can help."

Rebecca Hulme, Associate Director of Children, Young People and Maternity for the NHS Clinical Commissioning Groups in Norfolk and Waveney, said: "We've listened to what children and young people, their families and carers tell us is important in supporting their wellbeing, as well as looking at both local and national evidence into the best approach for providing access into mental health support in schools.

"We understand that mental health issues are a significant contributor to children and young people being absent from school, and impact on their wellbeing and relationships. Giving young people access to a range of opportunities, like talking therapies, one-to-one and group-based support, in school is an important step in working together to address their needs."

### Sign up for updates...

You can sign up for updates like the one above via the NCC website. Go to [www.norfolk.gov.uk](http://www.norfolk.gov.uk) and down at the bottom of the home page there is a 'Sign up for email updates' button. News will come directly into your inbox about all sorts of Norfolk developments and initiatives.

### Local Offer Facebook page

SEND Local Offer has a new Facebook page, which will be used as part of its SEND communication strategy, alongside Twitter and the SEND e-Newsletter (see page 4 of *this* newsletter). Please give the page a like and spread the word [@sendnorfolk](https://www.facebook.com/sendnorfolk)



## Family Voice Norfolk's summer 2019



August is usually a quiet month for Family Voice representatives but not this year! We've been working on a number of important workstreams that have not paused for a summer break. Here are just a few of them.

### Norfolk Area SEND Strategy 2019–2022

In the last newsletter we asked you to look at this document via the new **Special Educational Needs and Disabilities (SEND) policies and strategies** page of the NCC website or via the home page of the Local Offer at [www.norfolk.gov.uk/send](http://www.norfolk.gov.uk/send) and respond to the local authority's survey.

Family Voice Norfolk representatives also looked at the document and sent a detailed response to NCC. We had already responded to an earlier draft in 2018. Overall, although we do not disagree with the issues that have been chosen as a focus, we found that the document still uses a great deal of the kind of language that is commonly used within the local authority but that often obscures rather than clarifies meaning for those of us outside.

The document states that it will be amended following the survey and regularly reviewed, so we look forward to seeing what has been changed and to being able to continue to speak up for clearer, simpler statements of the improvements that we all know need to be made in how special educational needs and/or disabilities (SEND) are provided for in Norfolk.

### Learning Disability Health Checks

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

The health checks were instituted because it was found that the life expectancy and health outcomes for people with learning disabilities were significantly worse than

for the general population. The checks aim not only to look at a person's current health but also to ensure that the elements of a healthy lifestyle, such as diet, exercise, dental and eye care, are understood and supported as well as possible. By starting at the age of 14, a young person is helped to be as responsible for his or her own health as is possible and to feel that the surgery is a welcoming place to go in the future with any problems.

Unfortunately, the uptake of these checks is disappointing. Family Voice is helping to find ways to improve this, in the first instance, and to ensure that the checks are as helpful as possible as a further task.

Almost all GP surgeries in Norfolk offer the checks. The first step is to make sure that the young person is on **the GP's register** as having a learning disability.

**If you care for a young person who has experienced a Learning Disability Health Check and have any comments you would like to make about the service, please contact Kate on [membership@familyvoice.org.uk](mailto:membership@familyvoice.org.uk) or 07950 302937.** It is very useful for those representing Family Voice in meetings to have concrete examples of both good and not-so-good practice to share.

### Preparing for Adult Life interviews

Family Voice representatives have been sitting on the interview panels for posts in the new Preparing for Adult Life (PfAL) team that will launch later in the autumn. The position of parent carers with older children and young adults is a delicate one – we are trying to withdraw and encourage independence, giving young people their own say in their future, while often still offering vital support, guidance and nurture to our loved ones who have additional challenges in facing the world. We are making sure that candidates have a good understanding of a parent carer's role.



## Norfolk Learning Disabilities Strategy 2018–22

The **Norfolk Learning Disabilities Strategy 2018–22** has been published and you can find the full version, a summary and an easy read version at <https://www.norfolk.gov.uk/care-support-and-health/support-for-living-independently/learning-disabilities/norfolk-learning-disabilities-strategy> or by searching online for **My Life, My Ambition, My Future**.



## Guide to the Pupil Premium

The Education Endowment Fund (EEF) has recently published a new guide to the Pupil Premium, which is additional funding given to schools so that they can support their disadvantaged pupils and narrow any attainment and progress gaps between them and their peers. It is attracted by pupils receiving free school meals, by the children of those serving or who have recently served in the armed services, and by looked after children, including those who are adopted or under special guardianship. Schools are not obliged to spend the premium on individual pupils, as whole-school initiatives may well benefit those pupils more.

The Guide recommends schools take a tiered approach to Pupil Premium spending. Teaching should be the top priority, including professional development, training and support for early career teachers and recruitment and retention. Targeted support for struggling pupils should also be a key component of an effective Pupil Premium strategy; as well as strategies that relate to non-academic factors, including improving attendance, behaviour and social and emotional support.

You can read or download the whole report at [https://educationendowmentfoundation.org.uk/public/files/Publications/Pupil\\_Premium\\_Guidance\\_iPDF.pdf](https://educationendowmentfoundation.org.uk/public/files/Publications/Pupil_Premium_Guidance_iPDF.pdf)

Schools are obliged to publish on their websites:

- a strategy for the school's use of the pupil premium
- the school's pupil premium grant allocation amount
- a summary of the main barriers to educational achievement faced by eligible pupils at the school
- how the school will spend the pupil premium to overcome those barriers and the reasons for that approach
- how they will measure the effect of the pupil premium
- the date of the next review of the school's pupil premium strategy
- how the school spent the pupil premium allocation in the previous year
- the effect of the expenditure on eligible and other pupils in the previous year.

## Anaphylaxis treatment in schools

Since 2017, schools have been able to buy, without prescription, an adrenaline auto-injector (sometimes referred to as an epi-pen) for use in emergencies when a pupil's own adrenaline device is not available or not working. Excellent communication is vital so that schools know about pupils' allergies and parents know what will be done in an emergency. The government's advice to schools can be found at [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/645476/Adrenaline\\_auto\\_injectors\\_in\\_schools.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/645476/Adrenaline_auto_injectors_in_schools.pdf)

## Merging CCGs

The five Clinical Commissioning Groups (CCGs) in Norfolk and Waveney (Great Yarmouth and Waveney, North Norfolk, Norwich, South Norfolk, West Norfolk) are proposing to merge and would like your views.

You can read more about the plans in a document called **Moving Forward Together** via a link at <https://www.smartsurvey.co.uk/s/NorfolkandWaveneyCCGProposal>

This is also where you can find the survey to give your own views about the plans and to point out anything you think should be retained under the proposals.

## Young Epilepsy Guide

Young Epilepsy, the national charity for children and young people living with epilepsy, has launched a new online guide for schools. Find it at <https://www.youngepilepsy.org.uk/guide-for-schools/>

This guide is for people who work in schools or other educational settings. It provides information on supporting young people with epilepsy to ensure they are safe and included in all aspects of school life. Schools should ensure each young person with epilepsy has an Individual Healthcare Plan (IHP) and that the school has a policy on supporting pupils with medical conditions.

Good communication between the school, parents and the young person plays a key role in ensuring the right support is in place. All staff working with a young person with epilepsy should also be trained to understand the young person's condition and its impact on their life at school. State schools in England have a specific legal duty to support pupils with medical conditions and this support forms a crucial part of the school's safeguarding and equality duties.

The Young Epilepsy website also has a wealth of information for parent carers and children and young people themselves.

## Norfolk Community Directory

Do you run a local community group or do you know someone who does? Use the Norfolk Community Directory to promote your services and activities and get more people involved! Go to <https://communitydirectory.norfolk.gov.uk> to find out more.

NORFOLK COMMUNITY  
**DIRECTORY**



# CARING FOR A CHILD WITH ADDITIONAL NEEDS AGED 0-8 YEARS?

COME ALONG TO OUR FREE WORKSHOPS!

Our welcoming and informative sessions cover a range of topics, including:

Managing sleep | Encouraging positive behaviour  
How to get what you need for your child | Money matters

**Venue:** The Hamlet Children's Centre, Johnson Place, Norwich NR2 1SJ

**Dates:** Fridays 13, 20 and 27 September

**Time:** 9.45am (for tea, coffee and cake!) start 10am until 2pm

To book your places please email [bookings@contact.org.uk](mailto:bookings@contact.org.uk). Additional childcare costs can be covered. Please discuss when booking.

**contact** *For families with disabled children*



Contact is a trading name of Contact a Family. Charity registered in England and Wales (284912) and Scotland (SC039169).

## Friday 13 September

### Welcome session

Workshop agenda and getting to know each other

### Understanding sleep

- The importance of sleep and why sleep problems may occur
- How to introduce a sleep routine
- Top tips to help

## Friday 20 September

### Building parental confidence

- Develop better communication skills and recognise your strengths
- Feel more confident to make decisions about your child
- Prepare for meetings with professionals

### Encouraging positive behaviour

- Understand the reasons for behaviour
- Working with others to encourage positive behaviour
- Top tips to help

## Friday 27 September

### Money matters

- Know how to improve your finances
- Understand what you're entitled to
- Know where to get support

### Support for you

- Feel more confident in asking for support
- Relationship support and top tips
- Siblings support and top tips

Carers who can't attend all the sessions will be very welcome on the dates they are able to come. Lunch is provided.

Places can be booked via [bookings@contact.org.uk](mailto:bookings@contact.org.uk) or by ringing Helen Davies on 07966161753

These sessions are for adults only. There isn't a crèche but Contact can cover any additional childcare costs. Ask when booking.

Contact is a national charity supporting families of disabled children with guidance and information. <https://www.contact.org.uk>



## Grants for carers

The Norfolk Millennium Trust for Carers aims to offer unpaid carers a better quality of life by giving grants for practical items like washing machines and laptops, power packs for wheelchairs and short breaks.

Every year the Trust helps hundreds of carers across the county, young and old alike, from pensioners looking after a disabled spouse to children juggling schoolwork and the needs of a family member.

Grants of up to £300 can be applied for at any time on a form at <https://www.norfolkfoundation.com/funding-support/grants/individuals/norfolk-millennium-trust-for-carers/>

The website also gives full information about the kinds of things that are eligible for a grant. Those who have not applied before will have priority and the grant can't be used for something already paid for or for items solely for the use of the cared-for.

## 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](mailto:membership@familyvoice.org.uk)
- Or you can contact us via:



[www.familyvoice.org.uk](http://www.familyvoice.org.uk)



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



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

## NCC autism training

Autism awareness training is mandatory for all Norfolk County Council social care employees, delivered both by an e-learning programme and face-to-face in a one-day training course co-produced with autistic people and being rolled out across the council from July.

## Consultation about the use of restraint and restriction

This is a reminder that the Department for Education's (DfE's) consultation about whether there is a need for guidance for **mainstream schools, mainstream post-16 settings and alternative provision** on reducing the need for restraint and restrictive intervention continues until **17 October 2019**.

**Special schools** and health and social care settings already have this guidance. Read it at <https://www.gov.uk/government/publications/reducing-the-need-for-restraint-and-restrictive-intervention>

The DfE also wants your views on whether guidance should apply to a wider cohort of children and young people with SEND.

You can respond to the survey at <https://consult.education.gov.uk/send-alternative-provision-and-attendance-unit-sapau-analysis/guidance-on-reducing-restraint-and-restrictive-int/consultation/subpage.2019-06-25.7384995829/>