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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 07535 895748.

Do you have the right help for you?

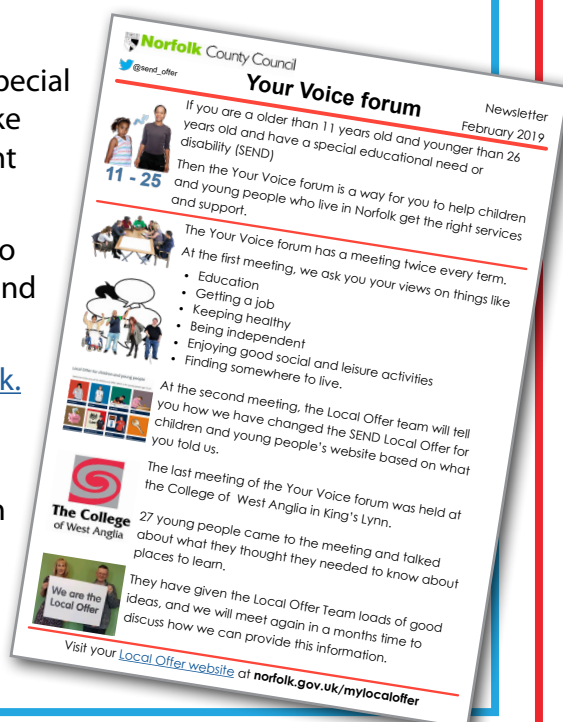
If you are older than 11 and younger than 26 and have a special educational need or disability (SEND), you can help to make sure that you and other young people like you get the right support.

The **Your Voice Forum newsletter** tells you how you can do this. It has a survey with questions about what helps you and how things could be better.

You can find a link to the newsletter at <https://www.norfolk.gov.uk/children-and-families/send-local-offer/about-the-local-offer/news-views-and-reviews/news/newsletters>

Take a look as soon as you can because the survey ends on **8 March 2019**.

You can ask a parent or carer to help you fill in the survey and send off your views if you like.



Family Voice Norfolk Ninth Annual Conference

Saturday, 16 March 2019

John Innes Centre, Norwich NR4 7UH

Keynote speaker:

Sara Tough
Director of Children's Services
on her vision for Norfolk

Booking

Places at this year's Conference are very nearly fully booked. If you haven't yet contacted us, go to the link on our Facebook page at <https://www.facebook.com/FamilyVoiceNorfolk> or visit our website at <https://www.familyvoice.org.uk/posts/news-events/>

Waiting lists

As usual, we will run a waiting list when the Conference is full. **Please**, if you have booked but find that you cannot attend after all, **let us know** at events@familyvoice.org.uk so that we can offer other families the opportunity. Let us know as soon as possible, of course, but even if your plans change on the morning of the Conference, contact us. We hate to turn people away only to find that we have space when others don't arrive.

Childcare

We are already running a waiting list for those needing childcare for a child with SEND. As last year, The Clare School is running this for us at their own site.

Workshops

We will be offering workshops on the following subjects. There is no need to book these.

Transition – Frank Crowdy, Norfolk County Council (NCC)

Just One Norfolk – Fay Spencer, NHS

Child and Adolescent Mental Health Service (CAMHS) – Rebekah Muttitt, Norfolk and Suffolk NHS Foundation Trust (NSFT)

SEN Support – Steph Askew, NCC

The ASD Pathway – Alan Hunter, Norfolk Community Health and Care NHS Trust (NCHC)

The Local Offer and Norfolk Directory – Claire Jones, NCC

Young Carers – Kevin Vaughan, Carers Matter

Annual Reviews of EHCPs – Janina Schiebler, SENDIASS

Speed dating

As usual, we are able to offer short one-to-one sessions with over a dozen professionals. Full details will be in the programme. These **do** need to be booked on arrival.

Stands

There will be more stands than ever featuring services and support for families with children and young people with special educational needs and/or disabilities (SEND).



**We are the
Learning Disability
'Liaison' Team**



Tara and Nic

**We work at the
Norfolk and
Norwich Hospital**



To contact Tara



01603 287862



tara.webster@nnuh.nhs.uk



To contact Nic



01603 287862



nic.smith@nnuh.nhs.uk

Our jobs are -

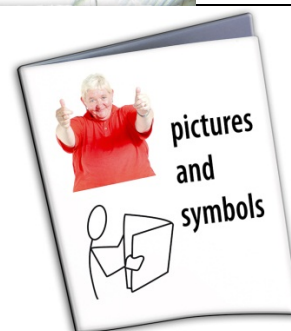
**To make your visit
to hospital better**



**To give hospital
staff training about
learning disabilities**



**To help the Hospital
be more accessible
to people with
learning disabilities**



Changes to funding of adult social care – further update

You will certainly have heard that the local authority's proposals to make savings in the funding of adult social care were passed at the full council on 11 February 2019.

The proposals included:

- young people should have a lower guaranteed income (MIG) than older people (and therefore pay more for their social care)
- those on the enhanced rate for daily living PIP payments should use this to help pay for their care.

This week, young people between 18 and 25 (and presumably others) have begun to receive letters from NCC about how the new calculations will be phased in.

NCC says:

- *From 22 July 2019, we will change the MIG for everyone aged 18–64. This means that their minimum income guarantee amount will be £165 a week instead of £189. We will also take an additional £9.00 of the enhanced rate of PIP into account when working out how much people must pay.*
- *From April 2020 we will change the MIG again for everyone aged 18–64. This means that their minimum income guarantee will be £151.45 a week. We will also take the full amount of the enhanced daily living element of PIP into account when working out how much people must pay.*
- *From April 2021 we will change the MIG for everyone aged 18–24 only. This means that the minimum income guarantee for this age group will be £132.45 a week instead of £151.45.*

We will write to you again in early March 2019 and again in May 2019.

In March 2019 we will let you know about annual benefit changes, and how much you will need to pay from April onwards. This is what we do every year when people's benefits change.

In May we will write to you about the changes to the minimum income guarantee and the Personal Independence Payment. This will explain how much you need to pay from July onwards.

As stated in the last newsletter, Family Voice Norfolk's response to these changes includes pointing out to the Executive Director of Adult Social Services the unfairness of targeting some of the most vulnerable people in our community, the real risks involved and the fact that although the local authority claims to work in co-production with parent carer forums and other representative bodies, Family Voice Norfolk was not involved in the discussions that led to these proposals.

Our role is to represent the views of parent carers, so please, if and when you know how these changes will affect your family, do let us know by any of the means suggested in this newsletter. We will always protect your anonymity, but having real stories of how lives are changed is so powerful when trying to show decision-makers what life is like for families with a young person with special educational needs and/or disability (SEND).

One parent told us:

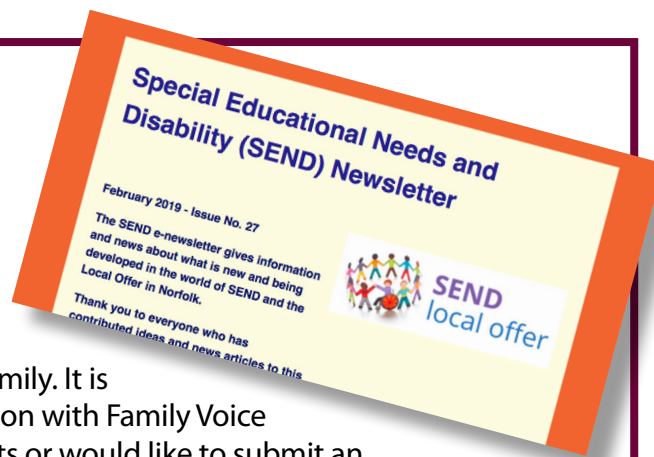
We have already had my daughter's personal budget cut this year and have had to ask for special bursaries to enable her to continue with the social inclusion activities that give her independence and a life outside our home – a life that I believe she is entitled to have as a young adult with a learning disability. I feel ashamed that I cannot myself give my daughter the life she deserves, but I shouldn't have to feel like that. She should be able to be an adult in her own right. I worry daily about what will happen to her when I am no longer here to advocate for her in a system that does not seem to understand what life is like for her.

Please let us hear your views, too.



SEND e-Newsletter

If you don't already subscribe to Norfolk's SEND e-Newsletter, or your subscription lapsed in the midst of the GDPR maelstrom, you can easily make sure you receive it at 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 bodies. If you have comments or would like to submit an article, you can contact the newsletter editors on send@norfolk.gov.uk



We look forward to seeing you at the

Family Voice Norfolk AGM

on Monday, 20 May 2019

at Ayton House, Ayton Road, Wymondham NR18 0QQ

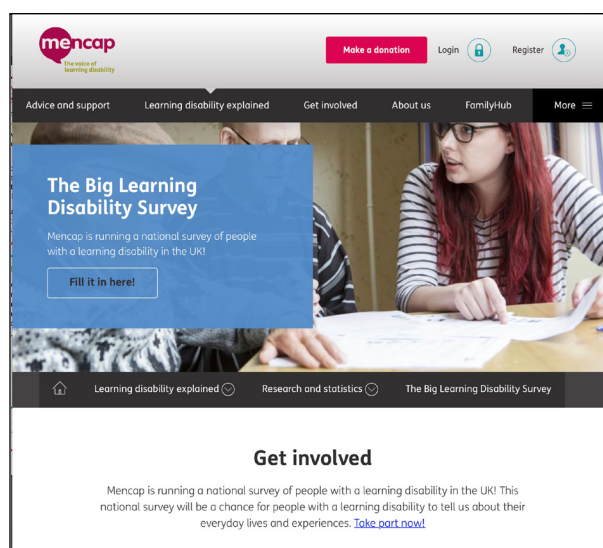
There will be a light buffet supper from 6.00pm to 6.30pm, when the meeting will begin.

If you would like to come, please leave Bernadette a message on 07535 895748 or office@familyvoice.org.uk so that she has catering numbers.

Mencap Learning Disability Survey

Mencap is running a national survey of people with a learning disability – a chance for adults of all ages with a learning disability to tell about their everyday lives and experiences. You can find the survey at <https://www.surveymonkey.co.uk/r/big-learning-disability-survey>

There is also a very useful guide to how to support someone with a learning disability to complete the survey so that their own views are captured.



Additional funding for speech and language therapy

On 20 February 2019, NCC announced that an extra £510,000 is being invested in speech and language therapy services in Norfolk each year, to help boost children's communication skills.



Norfolk County Council and Norfolk's Clinical Commissioning Groups (CCGs) have agreed the extra funding 'to help cope with increased demand on the service and ensure more children can get the help they need'. The extra investment is likely to be used to increase staffing, provide more support for families of pre-school children with complex needs and to develop an improved service to schools.

East Coast Community Healthcare (ECCH) will continue to provide speech and language therapy services in Norfolk, with the value of their contract increasing from £1.7m to £2.2m. The current contract runs until June 2021.

The extra investment means that from April, Norfolk County Council will invest £1.2m in the service and the CCGs will invest £980,000.

The extra investment follows a review of the service last year. Led by Better Communication CIC, the review found that there wasn't sufficient funding to cover the demand on services. It also said a more joined up approach was needed and that more staff were needed to carry out assessments, and plan and deliver specialist interventions.

How you helped

Back in the autumn of 2016, during Family Voice 'Round the County' parent participation events, we became aware that families had many concerns about the speech and language therapy (SaLT) services they were – or often were not – receiving.

We raised these concerns at Norfolk County Council's Health Overview and Scrutiny

Committee (HOSC) and were invited to bring evidence to the committee. You may have taken part in a survey we carried out in 2017. You can see our report of the results of the survey on our website at www.familyvoice.org.uk. Norfolk County Council and the CCGs then commissioned the review by Better Communication CIC (www.bettercommunication.org.uk), a not-for-profit community interest company. They support change for children and young people with speech, language and communication needs.

Family Voice Norfolk gathered more information from families at our Conference in 2018, where ECCH also ran a workshop, and at the beginning of May 2018 we also formed one of the focus groups giving evidence to Better Communication.

This is a subject that is important to many families and we intend to continue to monitor their views on the services our children and young people receive. If you are attending our 2019 Conference, do please visit the Family Voice stand and give us your views on any improvements – or the opposite – that you have already seen. We shall have our red and green cards at the ready for your responses on this and any other subject you would like to comment about.



We will also aim to follow up our 2017 survey later this year to see if the additional funding has resulted in better services for families.



Guidance for professionals when seeing clients with an Autistic Spectrum Disorder

Norfolk Community Health and Care NHS Trust (NCHC) has created some guidelines for professionals meeting with children and young people with ASD. It may be helpful to draw your own professional contacts' attention to these. We particularly like the emphasis on checking with parent carers what will be necessary to support their child.

The guidance ideas include:

- Ask the individual or parent/carer beforehand if there are any special needs to consider or reasonable adjustments which can be made to help make it a positive experience.
- Provide as much information as possible beforehand about what the appointment will entail and the location it will be held at.
- Where possible allocate the first or last appointment of the day so that delays are kept to a minimum.
- Provide a quiet room to wait in until they need to see the professional or allow them to wait in their car.
- If timings of appointments are running late then phone the parent/carer and let them know the new estimated time of the appointment.
- Allocate a longer appointment than usual.
- Flickering or buzzing fluorescent lights may cause discomfort. Check these regularly.
- Try and keep noise to a minimum and warn beforehand of any noisy equipment.
- Cold instruments and uniform items like masks may be frightening. Where possible, show the individual first and allow them to inspect before wearing.
- Carpeted areas provide less noise of clicking heels and scraping chairs, which are also noises that can distress.
- A step- by-step approach where the child is praised for just entering the building, then the corridor, then the appointment room, then sitting in the chair or lying on the examination bed may prove helpful.
- Be aware of the communication method of the individual. This may include symbols, photos, writing things down, sequences or signing, for example.
- There will always be some children for whom none of these will work and visits to professionals may be too much. In these cases home visits should be available to enable the child/young person to access their right to professional medical care and treatment.
- An action plan of steps agreed to take between professional and carer/child with agreed timings for appointments and timings to review would be most helpful.
- Social stories, visual cues and pictures of both location and staff can be useful ways to reduce anxiety and help an individual with Autism access new services.
- These ideas are not exhaustive and checking with the individual and/or their parent/carer is usually the most helpful way to better understand how to support them to access the service.



SEND System Leadership Board

Dame Christine Lenehan, following her review, *Good Intentions, Good Enough*, has been invited to join the newly formed SEND System Leadership Board.

As the review highlighted, when education works closely with health and social care, they commission services which better meet the needs of children and young people, supporting improved outcomes and effective use of resources.

The remit of the board will be to:

- Clarify and communicate the principles which should underpin all SEND commissioning and the good outcomes they are seeking to achieve for children and young people with SEND.
- Encourage improved joint working, commissioning and planning by and between education, health and social care partners.
- Identify where partners can better share data, insight, guidance, good practice and peer support to help encourage improved commissioning and planning, working to alleviate the long-term high needs budget pressures.

Increased capacity for specialist education team

NCC is investing £1.5m to double the size of its specialist education team in order to speed up assessments for education, health and care plans (EHCPs).

The intention is to complete a higher proportion of new EHCPs within the statutory 20 weeks, ensure that the quality of these documents also increases, and improve the considerable backlog of annual reviews in Norfolk.

Personalised Travel Scheme (PTS) update

The Personalised Travel Scheme (PTS) has been running now for almost a year, providing funding for families of Norfolk children with SEND to organise their own home-to-school transport, instead of being restricted to a taxi.

It has been very well received by parents and children alike, with journey times reduced and many of the issues of sharing a taxi with other high needs children being removed by families organising transport in the way they know best.

The opportunity for those interested in joining the scheme is now available until the end of the current academic year. This will give families more time to enjoy the benefits of the scheme and having more people take up this offer will give us a greater range of feedback on families' experiences.

This means there is still time for new families to join the scheme before the end of the summer term.

If you are interested in this scheme, or know someone else who might be, visit <https://www.norfolk.gov.uk/children-and-families/send-local-offer/about-the-local-offer/personalised-travel-scheme> or call Will Tait on 01603 223168.



Norfolk SEND Partnership

If you do not already receive it, you can find Norfolk SEND Partnership's Spring newsletter and/or subscribe to it at <https://www.norfolksendpartnershiass.org.uk> Norfolk SEND Partnership provides free and impartial information, advice and support about special education needs and disabilities (SEND) for children, young people, parents and carers. In the Spring newsletter you can find information about:

- Important dates if your child is moving from nursery to primary school, infant to junior school, or primary to secondary school in September 2019 and has an EHCP
- Part-time timetables
- Illegal exclusions
- Norfolk Steps
- EHCP annual reviews
- Making changes to an EHCP
- Independent Supporter (IS) update



TRIBUNAL Workshop Special Educational Needs & Disabilities

For parents wishing to appeal their final Education Health & Care Plan

WHERE

The Woodside Hub, Witard Road, Norwich, NR7 9XD

WHEN

20th March 2019
9.30 am – 12.30 pm

COST - FREE
Tea & Coffee available

GUIDANCE WITH

- Mediation
- Appeal Forms
- Preparing your case for appeal
- Appeal timetable
- Evidence needed

There will be some individual time slots available for individual support from 1pm after the workshop. These must be booked in advance by calling 01603 704070

TO BOOK - <https://tribunalworkshop2019.eventbrite.co.uk>

For more information call 01603 704070 or email sendpartnership.iass@norfolk.gov.uk

www.norfolksendpartnershiass.org.uk



Norfolk SEND Partnership is running the above Tribunal Workshop on 20 March 2019. Go to the website to find out more.

Remember...

At Family Voice we are always keen to hear your news or views about the services you are receiving or would like to receive.

We anonymise what you tell us and use it to affect decisions made by the education, social care and health authorities. Keeping us informed means that our representatives, who are themselves all parent carers of children and young people with SEND, can speak authoritatively about the

experiences of families like yours at the meetings and boards they attend.

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

- Or you can contact us via:



www.familyvoice.org.uk



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



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

Family Voice Norfolk newsletter deadlines

The next newsletter will appear at the end of March. If there are issues that you would like to see covered, please email comms@familyvoice.org.uk or leave a message on 07535 895748 before 24 March 2019.



Assessing pupils with complex disabilities: a new approach

The government has announced that a new approach that will enable primary schools to better assess pupils with the most complex needs will be rolled out across the country from 2020.

Around 7,000 pupils in primary schools have such complex needs that it would be inappropriate to measure their attainment in school according to the national curriculum tests.

The statutory assessment will replace P scales 1 to 4 and will be based on the '7 aspects of engagement', an assessment approach that focuses on pupils abilities in specific areas like awareness, curiosity and anticipation.

This assessment approach will – for the first time – enable every kind of progress made by these pupils to be identified. This addresses a key issue with P scales, which focused on linear progress, which is not always how children with the most complex needs progress. This will help teachers to best tailor their teaching and provision to meet the pupils' specific needs and to allow them to achieve the best possible outcomes.

You can find out more (and about other recent government announcements regarding SEND) at <https://www.gov.uk/topic/schools-colleges-childrens-services/special-educational-needs-disabilities/latest>

Annual National Conference of Parent Carer Forums

At the end of last year, 200 attendees representing 87 parent carer forums from across England attended Contact's and the National Network of Parent Carer Forums' (NNPCF) annual Parent Participation Conference in Coventry. Family Voice Norfolk is part of the NNPCF and Tracey Sismey, our Chair, attended on our behalf.

At the event marking an incredible 10 years of Contact supporting parent carer forums, key note speaker Children's Minister Nadhim Zahawi addressed the conference, noting that the growth in parent carer forum membership in the last 10 years has been 'staggering'.

At <https://contact.org.uk> you can find links to:

- a video of Nadhim Zahawi's key note speech
- a video about the difference parent carer forums have made in 10 years
- a video of Amanda Batter, CEO of Contact, on 10 years of parent carer forums
- Contact's annual parent carer participation review

Over the last 10 years parent participation has grown from a seed of an idea in 2008 with only 465 parent carers known to be involved in planning local services in England, to the influential movement it is today of almost 95,000 parent carers.

Gail Walshe, Contact Head of Parent Participation, said of the conference: "The collective noise and passion of so many parent carers in one place is very inspiring and everyone comes away with renewed energy for championing the changes they want to see for all families with disabled children." Our Chair would certainly agree! Overleaf is a fantastic visual representation of the energy and enthusiasm participants experienced.





ANNUAL NATIONAL CONFERENCE OF PARENT CARER FORUMS

contact

the **RIGHT** SUPPORT
at the **RIGHT** TIME

never **GIVE UP**
AS PROFESSIONALS
IT IS ESSENTIAL TO
COMMUNICATE CLEARLY
manage expectations well!

THE HEART OF THIS STORY...
IS THE COMING TOGETHER
of DIFFERENT APPROACHES
TO DRIVE CHANGE

93412 PARENT CARER MEMBERS!
OUR NUMBERS ARE EMPOWERING!
ON A NATIONAL LEVEL
WE KNOW WE CAN CHANGE THINGS

we will **MAKE CHANGE** HAPPEN!
PARENT CARERS NEED TO FEEL **OWNERSHIP**

Be Brave
CHAMPION the **CHANGE**

1st PRINCIPLE
we have a **COMMON** purpose

PARENT CARERS DON'T WANT A **ROLLS ROYCE**
WE WANT SOMETHING **RELIABLE**
we will keep on keeping on for **FUNDING & SUPPORT**

THIS IS NOT A PROCESS
IT IS A BELIEF SYSTEM
WE CHEN OVER ISSUES, COME TO RESOLUTION AND FIND SOLUTIONS THAT CAN BE IMPLEMENTED

IT IS REALLY **TOUGH** OUT THERE...
WE HAVE TO KEEP BEING **KIND** TO ONE ANOTHER & OURSELVES

EMOTIONS RUN HIGH, because **IT ALL MATTERS**

SPEAK TO POWER
OUR **VISION** FOR CHILDREN WITH SEND
IS THE SAME AS FOR ALL CHILDREN: TO REACH THEIR FULL POTENTIAL

where **CO PRODUCTION** happens, **ATTITUDES + OUTCOMES CHANGE**

WOW MOMENTS
PARENT CARERS NEED TO BE WELL INFORMED TO ENABLE GOOD DECISION-MAKING

ASK LISTEN DO
PARENT CARERS MUST GET INVOLVED
10 YEAR PLAN

NHS England IS COMMITTED TO HAVING PARENT CARERS VOICES HEARD
START WORKING WITH AND NOT AT FAMILIES & THEIR CHILDREN

SCHOOL
FOR CHILDREN WITH SEND
SHOULD BE THE GOAL FOR ALL OUR SCHOOLS.
& HAVE A HAPPY & FULL FILLED FUTURE

keep **FIGHTING THE GOOD FIGHT**
THE NATIONAL HELPLINE
THE PARENT CARER GUIDE TO DISAGREEMENTS

FORUMS HAVE BEEN PART OF A **CULTURE CHANGE** & THE IMPACT HAS BEEN **WIDE**

IT'S WHERE WE **Learn + Share + Build Trust!**
CONFERENCES MATTER!
OFFICE MAPPINGS

FUNDING RESULTS IN... **EMPOWERMENT**

Seashell NHS Trust
England

Department for Education

Scriberia