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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.

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



including a short presentation by **Shane Baxter**, Special Olympics World Games medallist, who will talk about his recent successes and his challenges and hopes for the future as a young person with SEND.

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.



Family Voice Norfolk Ninth Annual Conference – were you there?

Saturday 16 March saw our biggest Conference yet, with over 260 parent carers and their children attending a day filled with workshops, stands and opportunities to talk to over **one hundred professionals** from the health services, the local authority, support groups and many others.

It was lovely to see the friendly faces of parent carers who have been to many of our Conferences and continue to get so much from the day. It was also a wonderful opportunity for over 80 parent carers to attend our Conference for the first time. Many of them were keen to join as members of Family Voice Norfolk and have their voices heard.

We received lots of great feedback, highlighting what you liked and didn't like on the day. We will be looking at this carefully in order to make next year's Tenth Anniversary Conference better than ever.

You liked the keynote speech, the variety of stands, the workshops and the speed-dating sessions.

You wished that Sara Tough's speech allowed more time for questions and answers.

A full **report** about the Conference is being prepared. When it is ready we will feature it in this newsletter and put it on our website.

Some of your comments were bittersweet – we loved it that you gained so much from the Conference but were sad that information had not been readily available to you before.

The best day so far on this journey of ours...

Never knew there was so much help out there...

Next year will be our Tenth Anniversary Conference and we want it to be memorable – so watch this space!

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





Can your voice make a difference?

We all know that these are challenging times for those living or working with children and young people with special educational needs and/or disabilities (SEND). At Family Voice Norfolk we believe that at such times – more than ever – the real voices of parents and carers can make a difference. When budgets are tight, it's important that precious resources are used effectively – to help our children and young people to be equipped to live happy, fulfilling lives of their own choosing.

The knowledge that you have is invaluable to the local authority, social services and health services. As the Parent Carer Forum for Norfolk, Family Voice is invited to send parent/carers representatives to a wide range of meetings, boards and work streams. So often, we find there is a genuine desire to improve opportunities for our children with SEND but mistaken ideas about what families want or expect.

Our remit is not to campaign, although we often admire and agree with those who do. Our role is to clearly and carefully speak the truth of families' views and experiences, so that those who are not standing in our shoes can understand what we need and what our children need. We expect to be treated with respect and for our lived experience to be listened to.

We're looking for **representatives** and **ambassadors** to join our team.

Our **representatives** attend a variety of meetings, working with education, health and social care to ensure that SEND is always considered when planning services.

Our **ambassadors** attend events in their area and talk to parents like you about Family Voice, explaining what we do and publicising our Conference and other activities.

Following the success of our January Open Day, we invite you to another opportunity to come and find out more about what you can do if you have a few hours to spare during school hours.

Open Day

on Friday, 3 May 2019

drop in any time between 10.30am and 12.30pm

at Ayton House, Ayton Road,
Wymondham NR18 0QQ

Join us for a coffee and a chance to chat without pressure about what we do.

Representatives and ambassadors receive an hourly rate for attending meetings and travel costs are reimbursed. Full training and mentoring is given.

We are all parent carers of children and young people with special educational needs and/or disabilities (SEND), so we make sure that meetings are at family-friendly times and understand that you have other responsibilities.

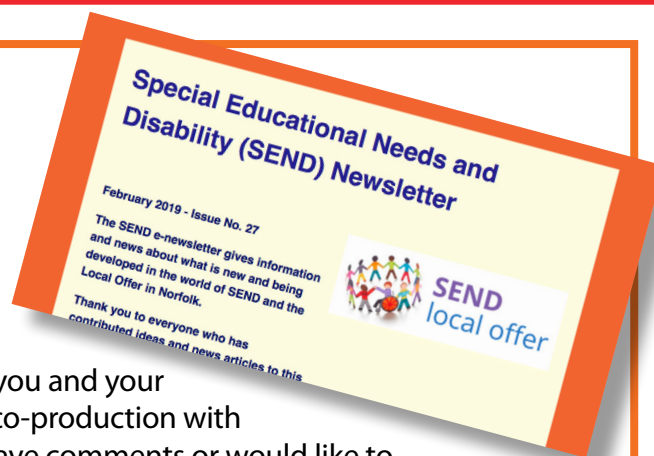
If you want to find out more before coming, or if you are not free that day, email Bernadette on office@familyvoice.org.uk or phone 07535 895748 and leave a message.



SEND e-Newsletter

If you don't already subscribe to Norfolk's SEND e-Newsletter, or your subscription has lapsed because you've changed your email address, 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



Travel and transport report

In the third series of sessions organised by Family Voice to give information and knowledge to parent carers while allowing them to share their family experiences with us, we focussed on travel and transport. For our sessions in November 2018, we invited Niki Park, NCC's Head of Passenger Transport; Wayne Doman, NCC's Local Offer Officer; Will Tait, NCC's Transport Officer; Karl Chapman, HCT's Independent Travel Manager; and Adam Curtis, NCC's TITAN Manager to work with us. Niamh Keane from SENDIASS was also invited to offer personalised advice to parent carers.

Some themes emerged from all the sessions:

- The Family Voice, Family Chat format enabled parent carers to gain knowledge and understanding of the SEND travel and transport policies and options, giving them a clear basis from which to articulate what was working or not working for their child or young person;
- By becoming better informed, parent carers are empowered to see how things can be improved, but are also able to appreciate good practice and service when they find it;
- Where travel and transport arrangements were working well, parent carers felt much less anxious about the subject generally;



- Transport arrangements are fragile and taxi drivers can leave without much notice. This can cause considerable stress and anxiety to parent carers and their children;
- Many parents are not aware of Meet and Greet sessions that are available prior to transport arrangements starting;
- 72% of parents were aware of Norfolk's Local Offer; 53% were aware of the Personalised Travel Scheme, 22% were aware of Independent Travel Training and 67% were aware of TITAN.
- As so often, the importance of good communication is key. The ability to have direct contact with NCC's Passenger Transport department, the willingness of some transport providers to make a real effort to know and understand the children and young people, and the flexibility of training providers were all very much appreciated.

You can read the full report on our website at <https://www.familyvoice.org.uk/wp-content/uploads/2019/03/FVFC-Report-November-2018.pdf>



Administration Assistant working from home for 15 hours / week – flexible working



Family Voice Norfolk is looking for an **Assistant to support the Administration Manager** in co-ordinating its activities. We are a group of parents and family members of children with special educational needs and disabilities (SEND). We work in partnership with service providers and decision-makers in Education, Health and Social Care to improve services for families like ours.

The successful applicant will assist with the day-to-day administration of Family Voice Norfolk and will need to have:

- good interpersonal skills
- excellent communication and organisational skills
- the ability to empathise with and understand the issues facing families of children with SEND
- the ability to use IT effectively, including MS Office.

Attendance at one or two meetings per month within Norfolk will be necessary, so a full driving licence and own transport is required. We aim to hold meetings at family-friendly times and, of course, will reimburse travel expenses. The working hours can be scheduled as suits you, but spread over the week is probably more effective than concentrated over a couple of consecutive days, as you may need to pass on last-minute changes to meetings or respond to urgent requests for information.

Applicants are invited to email a CV and covering letter, including details of two referees, to Bernadette at office@familyvoice.org.uk by **Tuesday 7 May 2019**. Further details can be supplied on request. A full description of the role can also be found on the Family Voice Norfolk website: www.familyvoice.org.uk

Norfolk SEND Partnership Tribunal Workshop

Thursday, **25 April 2019** 09:30 – 12:30 BST
The Woodside Hub, Witard Rd, Norwich NR7 9XD

This is a Tribunal Workshop run by Norfolk SEND Partnership for parents wishing to appeal their final Education, Health and Care Plan (EHCP). It will include guidance on mediation, EHCP appeal forms, preparing your case, the appeal timetable and the evidence needed.

You can contact Norfolk SEND Partnership by email at sendpartnership.iass@norfolk.gov.uk or via their website at <https://www.norfolksendpartnershiass.org.uk>

Contact via email will be made with all attendees before the training



Remember:

You have **two months** from the date of the Local Authority's decision letter or **one month** from the mediation certificate (which ever is later) in which to appeal.

Mediation must be considered before you can lodge an appeal. Contact **KIDS Mediation Service** on **03330 062835**.

More information is available in Norfolk SEND Partnership's booklets on their website, or telephone 01603 704070.



Speech, language and communication – please respond

We reported in the last newsletter about further developments in SLCN provision in Norfolk and how you can help to ensure that this improves.

We shall be seeking to add to our reports about families' experiences in more detail shortly, but in the meantime the local authority is asking for your views on a specific point.

In September last year, a councillor asked the commissioners of the speech and language therapy service why parents of children with special educational needs and/or disabilities (SEND) did not have a **single point of contact**.

While this sits outside the remit of the integrated speech and language therapy (SLT) service provided by East Coast Community Healthcare (ECCH), the Norfolk stakeholder group for speech, language and communication need is keen to understand what additional support a single point of contact would provide and how they can improve patient experience through what can be a complicated health and social care system.

This is a quick survey that should take less than 10 minutes but please do give your views. It can be found at:

<https://www.smartsurvey.co.uk/s/parent>



NORFOLK COMMUNITY DIRECTORY

How do you want to search for health service information?

As part of work to improve the integration between the SEND Local Offer and the Norfolk Community Directory, NCC is asking people to give views about how they would prefer to search for health services:

Option 1: by service type

Option 2: by type of need

Option 3: by searching all information.

There are two ways to give your views:

- by completing an online survey at <https://www.smartsurvey.co.uk/s/sendhealth/>
- by attending a Health Information Workshop on **Friday, 3 May 2019** at The Willow Centre, 1–13 Willowcroft Way, Cringleford, Norwich, NR4 7JJ
There will be workshops at **10.00 to 11:30am** and **12 noon to 1:30pm**

There is limited space so please email tim.webb@norfolk.gov.uk to book a place.

Support for young carers

Norfolk County Council has commissioned Carers Matter Norfolk to provide support for young carers and their families from 1 April. The service includes:

- A freephone seven-day-a-week Advice Line that can be reached by telephone or online LiveChat
- Activities and events to give young carers a break and the chance to socialise, as well as sessions to help them develop skills, confidence and resilience to balance the demands of caring.

It will also ensure young carers receive the assessment and whole-family support they need.

To make a referral to the service or find out more visit www.carersmatternorfolk.org.uk or call 0800 083 1148.



Finding what works...

Nicola writes:

When my son was about four and had newly arrived in my family, he used to march up to people and say, 'Hello, I'm Shane, I expect you've heard of me!' Then and later, when behaving well didn't get him the recognition and care he craved, he wouldn't hesitate to use challenging behaviour instead.



Long before we had useful diagnoses, I found that structured activities, where he felt 'seen' and was very clear about what was expected, reduced his anxiety and helped him participate when friendships and academic learning posed problems.

It meant we tried a lot of things that didn't work, though. Fencing? He was sent out for trying to stab someone in the back. Art classes? The over-flowing sink became his speciality. Tenor horn? Thank goodness we had insurance on the (hired) instrument.

Like many families with children with SEND, we also found groups and classes that *claimed* to be inclusive but didn't understand that this meant taking the time to find out about the needs and skills of the young person and asking how they could best be supported and included.

But we did find dancing (and a wonderfully inventive and supportive teacher) and when he was about 14, having enjoyed Special Olympics swimming, we heard about Special Olympics gymnastics and gave it a try. For a young person navigating the path from boyhood to manhood, it was a perfect fit. Male gymnastics is about strength and control – just what he needed.

We would never normally name young people with SEND in this newsletter, but last week Shane was interviewed on the sofa for *Look East*, and he has been

in the *Eastern Daily Press* and even the SEND e-Newsletter (see page 5 of this newsletter) so nowadays if he says, 'I expect you've heard of me!', a lot of people have. That's because in March he competed for Great Britain in gymnastics at the Special Olympics World Games in Abu Dhabi and had a life-changing two weeks there with the team. The highlight was winning medals, of course, but getting a selfie with Nicole Scherzinger came a close second...

Special Olympics is for children and adults with an intellectual (learning) disability. It's not elite – you can take part no matter what your ability and will compete against those at a similar level. What I love about it as a parent is that it isn't babysitting – it is properly about training and challenging yourself but in a safe and supportive environment. It shows that exams are not the only way of succeeding and the benefits in terms of health, self-esteem and feeling part of a team are huge.

Going to the Games hasn't 'fixed' Shane's life – he's still got a lot of challenges and needs to find a way into work and a future in which he can be as independent as possible but still have support when he needs it – but it has been a brilliant experience. With the World Games as a goal, he learnt to travel independently to training, working up to going to a squad in Glasgow on the train by himself. We kept in touch by text and phone and he sent me photos from the train (still needing to be 'seen' but technology is a wonderful thing for that).

The Local Offer (www.norfolk.gov.uk/send) and its link to the Norfolk Directory is a good way to find activities and opportunities. If your child or young person does something they love and it's not on there, encourage the group to ask for an entry, so that other families can benefit too. All our young people are individuals and finding what fulfils them isn't always easy, but it's worth it when you find it.

Consultation on learning disability and autism training for health and care staff

The government wants to know how it can make sure that health and social care staff have the right training to understand the needs of people with a learning disability and autistic people, and make reasonable adjustments to support them.

The consultation considers issues around the training and development staff need to better support people with a learning disability or autistic people.

The Department of Health and Social Care wants to know what people think about its proposals on:

- the planned content of the training
- how the training should be delivered
- how to involve people with a learning disability or autistic people in training
- how it can mandate, monitor and evaluate the impact of training

The consultation will be of particular interest to:

- people with a learning disability or autistic people
- the families and carers of people with a learning disability or autistic people
- patient groups
- providers of health and social care services working to alleviate the long-term high needs budget pressures.

To read the proposals and respond to the consultation, please go to <https://www.gov.uk/government/consultations/learning-disability-and-autism-training-for-health-and-care-staff>

The consultation closes at midday on **12 April 2019**.

Changing Places proposal

Seven new Changing Places facilities could be opened across Norfolk as part of a County Council proposal to make services more accessible.

Norfolk County Council's Policy and Resources Committee is being asked to agree £231,000 of investment so that the facilities can be developed in council buildings in each district.

Changing Places are accessible toilets and changing facilities for people with complex needs and disabilities. There are currently fewer than 1,000 across the country and fewer than 10 in Norfolk.

The Council wants to open them at centres being developed as part of its local service strategy, which aims to bring multiple services together under one roof.

Changing Places facilities need to include: a height-adjustable, adult-sized changing bench; a ceiling track hoist system; adequate space for the user and up to two assistants; a privacy screen; large waste disposal bin and a washbasin.

Standard accessible toilets meet the needs of many people with disabilities, but the Changing Places Consortium says there are 230,000 people in the UK who need assistance to use the toilet or change continence pads, including those with profound and multiple learning disabilities.

The first of the multi-functional centres is due to officially open at Attleborough Community and Enterprise Centre this summer, with the library service moving in this spring. The centre, which is owned by the County Council, is also used for early education and childcare.

The Changing Places facility is expected to be in place by the summer.

The Policy and Resources Committee was due to meet on 25 March to decide whether to approve the capital funding for the Changing Places facilities.

SEN Information Report Good Practice Guide

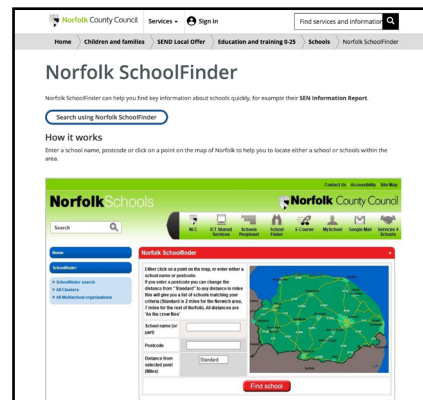
In earlier newsletters we drew your attention to the fact that schools must publish detailed information about their provision for students with special educational needs and/or disabilities (SEND) on their website. The local authority has now produced a *SEN Information Report Good Practice Guide* so that schools and those interested – including parent carers – can see what is expected.

Parent carers can use Norfolk Schoolfinder at <https://www.norfolk.gov.uk/children-and-families/send-local-offer/education-and-training-0-25/schools/norfolk-schoolfinder> to find information about Norfolk schools, including quick links to published SEN Information Reports.

All educational settings should:

- publish information about their SEND offer
- review and update this information annually
- involve parent carers in its review and development and
- use the SEN Information Report Best Practice Guide to help them.

The County Council regularly checks that educational settings have published an up-to-date SEN Information Report. The next audit will take place during November and December 2019 and include a quality assurance of a randomly selected sample of settings. If your school's SEN Information Report is not as full or up-to-date as it should be, you can ask your SENCo when parent carers will be involved in its review.



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



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

Family Voice Norfolk newsletter deadlines

The next newsletter will appear at the end of April. 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 23 April 2019.

Wishing all our readers a happy and peaceful Easter break

