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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.

We look forward to seeing you at the

## **Family Voice Norfolk AGM**

**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](mailto:office@familyvoice.org.uk) so that she has catering numbers.



# Family Voice Norfolk Ninth Annual Conference

## Saturday 16th March 2019 at the John Innes Centre



Bernadette Pallister, Administration Manager for Family Voice Norfolk, reports on this year's Conference:

The Conference began with a 'real buzz' when Sara Tough, the Director of Children's Services at Norfolk County

Council, opened Family Voice Norfolk's ninth annual Conference for parent carers of children with special educational needs and/or disabilities (SEND). She spoke about the SEND Transformation Programme and how this investment will provide more spaces for children in Specialist Resource Bases (SRBs) and new special schools. Many parent carers came to the Conference specifically to see Sara's presentation and to find out more about the Transformation Programme. Some were disappointed that there was not more time at the end for questions. We will bear this in mind when planning next year's tenth anniversary Conference.



Over 370 participants attended the 2019 Conference, making it our most popular to date. Of this number, over one hundred were professionals offering stands, workshops and the opportunity to talk to parent carers one-to-one. There were eight workshops, over 40 stands and more than 60 speed-dating sessions.

The morning workshops covered the popular topic of Preparing for Adult Life, the new Health digital platform called Just One Norfolk, a presentation on the Autism Spectrum Disorders (ASD) Pathway (standing room only) and the local authority's guidance for educational settings on the Provision Expected at SEN Support level.

Our ever-popular and over-subscribed speed-dating sessions were held over the lunchtime period. Fourteen professionals offered their time to talk, one-to-one, with over 60 parent carers, many of whom felt that this was the most useful part of their day.



The afternoon workshops included a question and answer session with professionals about Child and Adolescent Mental Health Services (CAMHS), a presentation about the new service available for Young Carers, an 'engaging' workshop for young people to capture their views in the Local Offer and a presentation about Reviewing an Education, Health and Care Plan (EHCP). Nearly 200 parent carers attended the workshops and presentations will be available on our website shortly.





As well as the many stand holders who regularly attend our Conference, this year we included several new stands to give families increased variety, including local and national SEND charities, healthcare organisations, NHS service providers and services from the local authority. Stand holders value the opportunity to meet and talk to parent carers and network with other professionals.

The Family Voice Norfolk ambassador team ran our own stand where parent carers were able to find out more about the work that Family Voice is involved in and sign up to become a member or to join the team. It is excellent to be able to talk directly with parent carers – after all, expressing families' views to decision-makers and planners is what we are all about. Our motto is 'together we are stronger', so the more voices we can represent through our membership, the more we can positively affect the services that we all need for our children and young people.

Each year we ask parent carers and professionals for feedback about the Conference, which assists us with preparation for the following year. This year 100% of those parents who filled in their feedback forms said that they would recommend the Conference to a friend and 95% said that they would come along next year. The other 5% have children who will be over 25 by this time next year.

It was lovely to see the friendly faces of parent carers who have been to many of our Conferences over the years and continue to get so much from the day. We were also delighted to welcome over 80 parent carers who attended for the first time. Many parent carers are not aware of all the services and support available and the Family Voice Conference is an important annual event that allows them to come together and realise that they are not alone. Many find the Conference day a wonderful chance to network with other parents and catch up with old friends.

Details of the feedback from parent carers and professionals will soon be available on our website at [www.familyvoice.org.uk](http://www.familyvoice.org.uk). If you would like a hard copy of this report or any of the presentations, please email [office@familyvoice.org.uk](mailto:office@familyvoice.org.uk) or write to us at Family Voice Norfolk, PO Box 1290, Long Stratton, Norwich, NR15 2HD.

We would like to thank all the parent carers and professionals who attended for making it such an amazing and successful day. Next year is our tenth anniversary Conference, so we welcome any ideas you have to make it an even more memorable experience.



*See you next year!*





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

### NORFOLK COMMUNITY DIRECTORY

#### How do you want to search for health service information?

There is still time to take part in a survey about how you would prefer to search for health services for children and young people with SEND on the Local Offer.

Work is being undertaken to improve the integration between the SEND Local Offer and the Norfolk Community Directory. The survey gives you three options of how to search:

Option 1: by service type

Option 2: by type of need

Option 3: by searching all information.

If you were not able to attend the workshop on 3 May, you still have until **24 May** to give your views via the quick online survey at <https://www.smartsurvey.co.uk/s/sendhealth/>

Please do respond if you have a minute. If you've ever found it difficult to find a piece of information on the Local Offer or elsewhere, here's a chance to explain how you like to search.

#### 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](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 bodies.

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)

#### Special Educational Needs and Disability (SEND) Newsletter

April 2019 - Issue No.28

The SEND E-Newsletter gives information and news about what is new and being developed in the world of SEND and the Local Offer in Norfolk.



Thank you to everyone who has contributed ideas and news articles to this edition.

#### World Autism Awareness Week 1st - 7th April

Pioneered by the National Autistic Society (NAS), World Autism Awareness Week aims to draw attention to the 700,000 people living with autism in the UK - both to educate those unaware of the condition, and to help make the world friendlier to those who are affected by it.

Norfolk Autism Partnership Board is holding a special event at The Forum on Friday 5 April, 10am - 4pm to mark World Autism Awareness Week.

At the event a range of partners will share information and offer guidance and advice about the support on offer to autistic people in Norfolk.

This is a great opportunity to find out about Autism Spectrum Disorder, take part in activities and hear from autistic people. Everyone's welcome to drop in at any time.





## Are you following us on Facebook?

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

We're always looking for ways to reach out to the SEND community – families with children and young people with special educational needs and/or disabilities and those who support or work with them.

As a [parent carer forum](#) we are not a campaigning group or a support group but a **voice** – we're all parent carers or close family members of children and young people with SEND, and our remit is to represent the views of families like ours to decision-makers and planners in the local authority, health and social services.

So increasing our membership (it's free and easy to apply at <https://www.familyvoice.org.uk/contact/join/>) and hearing your views and experiences is vital for us, but we also try to give you news about what we're doing and insights into services and changes to services in this newsletter, our Family Voice Family Chat events, our Conference and in other ways.

Sometimes, though, we only get to hear about something that might interest you a couple of weeks or less beforehand – too late for our monthly newsletter. We talked about it at our steering group and decided that we needed to be more active on social media.

Lisa Lonergan, our Ambassadors Lead, has begun invigorating our [Facebook page](#) to give you lots of information about all of the above but also a wide range of events that might be of interest to your family. Honestly, it's been amazing to discover how much is going on all over Norfolk.

On the right is just one example of a good outcome from a post.

**So if you haven't, please follow us!**

## Family Voice and football!

Not a heading I ever thought to write...

Following on from a post on our Facebook page that highlighted the need for a sensory pack for our children and young people at football grounds – similar to one Ipswich Town are introducing – Family Voice have been in contact with Norwich City FC, and they do have plans to introduce a pack this July/August.

As they are now in the Premier League (well done, Norwich!), they are now governed and led by the Premier League as to what the pack looks like. If permitted, they may be able to consult with us as to what the pack contains. If this is the case we will, of course, reach out to our families for input. It will most likely mirror the Ipswich bag, which contains a disability awareness lanyard, a map of the ground, noise-cancelling earphones, a fidget spinner and a stress ball.

Follow us on Facebook to make sure you hear more news on this and other SEND developments.



**COMMUNITY  
SPORTS  
FOUNDATION**

Don't forget that NCFC's official charity partner, the Community Sports Foundation, has a wide range of programmes for children and young people with SEND, including dance, exercise in water and multi-sports as well as football. Disability Match Day Clubs offer both coaching and tickets to see Norwich City in action.

Find out more at <https://www.communitysportsfoundation.org.uk> under the Programmes and Disability tabs.





## Safe places

The **Safe places** scheme, run by Norfolk County Council, is for anyone who needs extra help and support when they are out in the community. The scheme is for anyone aged 11+ who might feel vulnerable or scared when out in public places. This could be someone with a learning disability, sensory impairment, autism, dementia, mental health issues or physical disabilities. If there's a

problem – a bus hasn't arrived, for example, or a person or group on the street is causing anxious feelings – the vulnerable person can find a Safe place where someone will help them.

Anyone can join the scheme and get a **Safe places card**, which you can carry with you. If you are out on your own and encounter a problem or difficulties, you can go to a Safe place and show your card. Someone will help you make a phone call to a friend, a family member or the emergency services and wait with you until they come.

The idea is that being a member of the scheme will give you the confidence to be independent within the community. It has been developed with Norfolk Constabulary. By linking your phone to the Safe places website, you can quickly find where the nearest Safe place is.

More details, including how to get a Safe places card and an Easy Read version of how the scheme works, can be found at <https://www.norfolk.gov.uk/safety/safe-places>



## 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](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)

## Family Voice Norfolk newsletter deadlines

The next newsletter will appear at the end of May. 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 May 2019.



## Review of the National Autism Strategy

In April 2014 the government published 'Think Autism', a strategy for meeting the needs of autistic adults in England. The strategy supports the Autism Act 2009.

This year the Department of Health and Social Care, working with the Department for Education, will review the strategy and extend it to cover children as well as adults.

To help to do this, the government wants to hear about people's experiences of care and support.

This call for evidence is for England only. It will be of particular interest to:

- autistic people – adults, children and young people
- their families
- their carers
- organisations and professionals that provide care and support to autistic people or work with autistic people

The results will be used to find out where people think progress has been made and where more needs to be done in the future.

Many of you will have a lot to say on this subject, so please go to the survey at <https://consultations.dh.gov.uk/autism/2e4ae18d/>

The **closing date** is **16 May 2019**.

## Online consultations with GP practices

A new IT system means local GP practices can now offer online patient consultations, and 30 practices across Norfolk and Waveney have already expressed an interest. You may like to ask if your own practice has this service or is planning to introduce it. For parent carers of children with special educational needs and/or disabilities (SEND), who may struggle with transport or find it hard to access the practice for themselves alongside caring for children, this could be really helpful.

## Nurse training

In April, three Family Voice parent carer representatives were invited to speak to trainee nurses, with some specialising in learning disabilities. We talked frankly about our experiences as parents of children with learning disabilities, medical and mental health needs. Few of the (mainly) young people before us had much experience of the realities of our lives, but they were so grateful for the insights we were able to give. There was a lot of laughter as well as serious points to make. Our love and support for our children and our wish for others to see them as individuals was very clear. It was a pleasure to speak about something so near to our hearts and to be told how helpful our stories of good and bad practice had been. When our views are valued and helpful, being a Family Voice rep is a great job. Do get in touch with us if it's something you might enjoy too.





## Education technology strategy (EdTech)

The new Education technology (EdTech) strategy, *Realising the potential of technology in education*, has just been published by the Department for Education. You can find the full strategy, or a shorter summary, at <https://www.gov.uk/government/publications/realising-the-potential-of-technology-in-education>

This strategy highlights the opportunities of technology (including assistive technologies to support increased function, motivation, independence and access to learning) and is the Department's first step in supporting the education sector to overcome the barriers to embedding technology in an effective and efficient manner.

It sets a number of 'EdTech challenges' to industry, the education sector and researchers to prove what is possible and inform the future use of EdTech across education. They are designed to support a partnership between the EdTech industry and education sector to ensure product development and testing is focused on the needs of the education system.

To support the challenges, the DfE will establish:

- A series of innovation competitions
- A small testbed of schools and colleges to support the development, piloting and evaluation of technology
- Leading demonstrator schools and colleges, which will build on existing good practice to exemplify how these technologies can be used to best effect.

One of these challenges is to **'identify the best technology that is proven to help level the playing field for learners with special educational needs and disabilities.'**

## Direct Payment Support Service

Norfolk County Council's Direct Payment Support Service is now in operation to help those who receive direct payments and the personal assistants (PAs) they may employ.

The following services are available:

- Employer support, advice and training
- A PA register of personal assistant carers in Norfolk
- Payment services (payroll), where DPSS helps you with payments to your employee
- Training for working PA carers, or those who wish to work as one.

DPSS has also produced two online guides to help you if you are a direct payments employer or want to work as a PA carer.

You can access information about DPSS at <https://www.norfolk.gov.uk/dpss> or email [DPCST@norfolk.gov.uk](mailto:DPCST@norfolk.gov.uk) or telephone 01603 223392.

To give feedback about the service, email [DPSSFeedback@norfolk.gov.uk](mailto:DPSSFeedback@norfolk.gov.uk).

A Family Voice member has commented: 'Our PA looked at the website and some of the information given is not very clear and leaflets don't spell out any costs to service users. The PA training is free, for example, if your PA earns less than £15,736 a year and has lived in the UK, EU or EEA for three years before the start of the course. But if your PA has not been here so long, or has another job as well (as ours has), then one morning's training appears to cost £500, according to the website. In fact, there is online learning as well and perhaps other face-to-face sessions, but following links just takes you round in a circle without giving more information.'

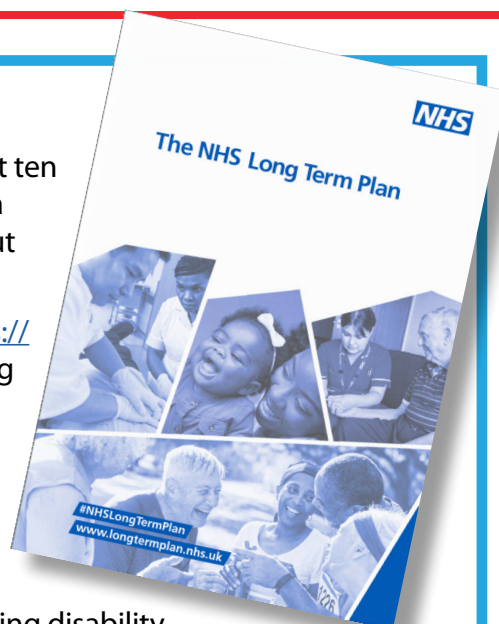
This is a new scheme, so please do give feedback if you find other aspects of it difficult to navigate or misleading. If you are wary of seeming to 'complain', let us know what's not working for you and we will represent your views anonymously.



# The NHS Long Term Plan

In January, the NHS launched its Long Term Plan for the next ten years. Headlines focused on heart attacks, strokes, dementia and mental health, but what does the plan have to say about learning disability and autism?

You can download the whole of the Long Term Plan at <https://www.longtermplan.nhs.uk> but basically the plan for learning disability and autism has six parts.



## **1. Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people. The plan is:**

- to improve uptake of the existing annual health check in primary care for people aged over 14 years with a learning disability, so that at least 75% of those eligible have a health check each year.
- to pilot the introduction of a specific health check for people with autism and, if successful, extend it more widely.
- to continue to expand the STOMP-STAMP programme to stop inappropriately prescribing psychotropic medicine to people with a learning disability or autism.
- to continue to fund the Learning Disabilities Mortality Review Programme (LeDeR), 'the first national programme aiming to make improvements to the lives of people with learning disabilities'. [Not sure what this means. The *length* of lives?]

## **2. The whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing. The plan is:**

- to deliver awareness training to NHS staff on supporting people with a learning disability and/or autism.
- Sustainability and Transformation Partnerships (STPs) and integrated care systems (ICSs) will be expected to make sure all local healthcare providers are making reasonable adjustments to support people with a learning disability or autism.
- over the next five years, national learning disability improvement standards will be implemented and will apply to all services funded by the NHS. These standards will promote greater consistency around rights, the workforce, specialist care and working more effectively with people and their families.
- by 2023/24, a 'digital flag' in the patient record will ensure staff know a patient has a learning disability or autism.
- the NHS will work with the Department for Education and local authorities to improve their awareness of, and support for, children and young people with learning disabilities, autism or both.
- the NHS will work with partners to bring hearing, sight and dental checks to children and young people with a learning disability, autism or both in special residential schools.

**3. Over the next three years, the NHS will work to reduce waiting times for specialist services for children and young people with suspected autism. The plan is:**

- include autism diagnosis alongside work with children and young people's mental health services to test and implement the most effective ways to reduce waiting for diagnostic assessments.
- with local authority children's social care and education services, as well as expert charities, the NHS will jointly develop packages to support children with autism or other neurodevelopmental disorders including attention deficit hyperactivity disorder (ADHD) and their families, throughout the diagnostic process.
- by 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker. Initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to hospital. Keyworker support will also be extended to the most vulnerable children with a learning disability and/or autism, including those who face multiple vulnerabilities such as looked after and adopted children, and children and young people in transition between services.

**4. Continue to decrease the number of those with a learning disability and/or autism in long-term inpatient care and move more care into the community. The plan is:**

- to give local providers control of budgets to reduce avoidable admissions, enable shorter lengths of stay and end out-of-area placements.
- where possible, people with a learning disability, autism or both will be enabled to have a personal health budget (PHBs).
- by March 2023/24, inpatient provision will have reduced to less than half of 2015 levels and for every one million adults, there will be no more than 30 adults and no more than 12 to 15 children with a learning disability and/or autism cared for in an inpatient unit.

**5. There will be increased investment in intensive, crisis and forensic community support**  
The plan is:

- to enable more people to receive personalised care in the community, closer to home and reduce preventable admissions to inpatient services.
- every local health system will be expected to use some of this growing community health services investment to have a seven-day specialist multidisciplinary service and crisis care.
- the NHS will continue to work with partners to develop specialist community teams for children and young people.

**6. There will be a focus on improving the quality of inpatient care across the NHS and independent sector.**The plan is:

- by 2023/24, all care commissioned by the NHS will need to meet the Learning Disability Improvement Standards.
- the NHS will work with the CQC to implement recommendations on restricting the use of seclusion, long-term segregation and restraint for all patients in inpatient settings, particularly for children and young people.
- All areas of the country will implement and be monitored against a '12-point discharge plan' to ensure discharges are timely and effective.

