

# newsletter

May 2019

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If there are issues you would like to see in future newsletters, contact <a href="mailto:comms@familyvoice.org.uk">comms@familyvoice.org.uk</a> or leave a message on 07535 895748.

## Family Voice Norfolk AGM

Our Annual General Meeting was held on 20 May. If you were not able to come, the full AGM Report can be found on our website at <a href="https://www.familyvoice.org.uk/articles-reports/agms/">https://www.familyvoice.org.uk/articles-reports/agms/</a>

Shane Baxter, a young man with SEND, spoke about how Special Olympics had changed his life. To find out more about Special Olympics Norfolk and Special Olympics GB, go to <a href="https://www.specialolympicsnorfolk.com">https://www.specialolympicsnorfolk.com</a> and <a href="https://www.specialolympicsgb.org.uk">https://www.specialolympicsgb.org.uk</a>

It was great that other young people with SEND spoke up at the meeting. Our remit is to ensure that the voices of families are heard by decision-makers and planners, and 'families' include parent carers, siblings, wider family, and children and young people with SEND themselves.

To give us your views about how services or lack of them affect your family at any time, contact our Membership Secretary Kate on 07950 302937 or email her at <a href="mailto:membership@familyvoice.org.uk">membership@familyvoice.org.uk</a>



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# 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 <a href="mailto:events@familyvoice.org.uk">events@familyvoice.org.uk</a> or call/text on 07535 895748.

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

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# Family Voice Five-Minute Focus survey on Speech and Language Therapy (SALT) services



Family Voice Five-Minute Focus is back to find out your experiences and views about Speech and Language Therapy (SALT) services with a very short survey.

Over the last year, SALT services have been the focus of the Health Overview Scrutiny Committee (HOSC) and Family Voice have been presenting the views and experiences of parent carers to this meeting.

We are now looking at the access to SALT services and would like to hear from parent carers who are currently accessing or trying to access these services.

If your child or young person (0–25 years) currently has additional communication needs, we would really appreciate **five minutes of your time** to find out your views and experiences.

We will be providing a report to the HOSC meeting in October 2019, ensuring that all responses are completely anonymised and unidentifiable. You can find a link to the survey on the Family Voice website at <a href="https://www.familyvoice.org.uk/posts/participation-opportunities/">https://www.familyvoice.org.uk/posts/participation-opportunities/</a>

Please complete the survey by Friday 19 July 2019.

Together our voices are stronger.

## Call for evidence on SEND funding arrangements

In December 2018, the Secretary of State announced an intention to hold a call for evidence on the current funding arrangements for those with special educational needs, those with disabilities, and those who require alternative provision.

This call for evidence is intended to help government understand how the current available funding is distributed, and what improvements to the financial arrangements could be made in future. There is also an awareness of the wider concerns about the overall amount of funding and the pressures on their budgets that many are reporting: the government is separately looking carefully at this ahead of the next government Spending Review.

The call for evidence can be accessed at <a href="https://www.gov.uk/government/consultations/send-and-ap-provision-call-for-evidence">https://www.gov.uk/government/consultations/send-and-ap-provision-call-for-evidence</a> and will be open from now until 31 July 2019.

This is a long and complex survey, taking several hours to complete. It is mainly aimed at educational settings, local authorities and other groups and bodies. You have told us many times that schools are citing lack of funding as a reason for reduced or non-existent support for children and young people with SEND. If you want to respond to the survey, by all means do so. If not, you could help by:

- urging your school or setting to respond themselves to the call for evidence;
- contributing to an upcoming Family Voice Norfolk survey. We will respond to the full survey on behalf of families in our region but of course the more we hear from you on the subject, the more powerful our response can be. Our survey will <u>not</u> take hours to complete but is aimed at making it easy for you to give us your own experiences of SEND funding issues. Please do complete it, however briefly, when it reaches you.



## 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 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



## SEND e-Learning Course

A new SEND e-Learning Course is now available. You can find it on the Local Offer at www.norfolk.gov.uk/send via the Training, Events and Things to Do tab on the home page or directly from here.

This course gives learners a foundation knowledge and understanding of SEND for children and young people aged 0-25.

It has been designed to support the professional development of those who work, or are training, in the field of SEND, but 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 but do read the note in the intro about allowing time to complete these.

The course was co-produced by a small group with representation from Norfolk County Council, the Clinical Commissioning Groups, Norfolk SEND Partnership and Family Voice Norfolk.

If you take the course, please do give us your feedback in any of the usual ways (see below!)



## 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**
  - <u>familyvoicenfk</u>



# Fairstead Primary Care Consultation



A public consultation has been launched about the provision of primary care services to residents of Fairstead in King's Lynn.

Healthwatch Norfolk would like your feedback on the consultation document. You may choose to give feedback anonymously if you wish.

You can view the consultation document and, if you are a resident of Fairstead, take the survey on the Healthwatch Norfolk website at https://www.healthwatchnorfolk.co.uk

There will also be opportunities for Fairstead residents to share their opinions at a series of public workshops, where individuals can discuss the matter with representatives from Vida Healthcare and West Norfolk CCG. The workshops are on 11 June, 9 July and 14 August. Details can be found on the Healthwatch Norfolk website, where you can also book a place.

The consultation closes on 30 August 2019.

# Pop-up Changing Places family weekend 10–11 August 2019

Following recent feedback from a Norfolk mum who has four children with additional needs, for this weekend in the summer Pensthorpe Natural Park near Fakenham is trialling a Mobiloo (pop-up Changing Places facility).



There are over a quarter of a million people in the UK for whom a standard accessible toilet does not meet their needs. They either need a bit more space, or need to be able to use an electronic hoist or changing bench in order to go to the toilet. The choice facing such individuals and their families or carers is to simply stay at home, or to risk injury and infection by getting changed on a public toilet floor. Trialling a Mobiloo at Pensthorpe means people aren't forced to make this choice. Standard accessible toilet facilities are not widely available and Pensthorpe is seeking to be inclusive as well as considering permanent facilities as part of the longer term planning of its facilities.



The Mobiloo will be available with hoist, adult-sized changing bench and all else you'd expect to find in a fully accessible toilet. It will also be fully attended. The attendant will be able to instruct potential users if they are unsure how the equipment works.

The Mobiloo will be at Pensthorpe between 9am and 6pm.

For further information, go to <a href="https://www.pensthorpe.com">www.pensthorpe.com</a> or telephone 01328 851465 (ex 2).

## Thank you and welcome...

At our AGM on 20 May, Wayne Doman stood down from our steering group. He was not able to attend the AGM, so we would like to take this opportunity to say that he will be missed and to thank him for all his help and advice.

We were delighted, however, to welcome these three new steering group members: (from left to right) Pamela Durham-Green, Julia Fromings Hill and Rachel Clarke.







Although our reps and ambassadors are paid for their time and expenses, the steering group role is voluntary as far as 'steering' is concerned – deciding on Family Voice's work plan and overseeing that it is developed and progressed, making decisions as necessary. Some specific tasks that we would otherwise need to pay someone to do are paid for, however, and we also have three paid staff roles: our Membership Secretary, Admin Manager and Admin Assistant. Sam Booker, our first Admin Assistant, also stepped down around the time of the AGM, though we are delighted that she will continue to help us with IT projects.

After advertising, we had a huge amount of interest in the Admin Assistant's role, with some very highly qualified applicants. We are delighted to announce that we have

appointed Emma Parncutt, who will start work in June. Emma will co-ordinate the increasing number of meetings our reps attend with the local authority, health and social services.



# Norfolk County Council cabinet

Following the elections in May, Andrew Proctor has been re-elected as leader of Norfolk County Council and has formally appointed a new cabinet leadership team.

The Council's current service committees are replaced with:

- A 10-member cabinet, which takes key decisions – the full council will continue to decide the annual budget
- A scrutiny committee, to hold the administration to account
- Three select committees corporate, infrastructure and development, and people and communities – to develop policy.

The cabinet members most relevant to those of us with an interest in special educational needs and/or disabilities (SEND) are:



Andrew Proctor, leader: Governance and Strategy



Bill Borrett: Adult Social Care, Public Health and Prevention



John Fisher: Children's Services

All current cabinet members are Conservative councillors.

# NNUH Children and Young People's Learning Disability Liaison Team





Fiona - Children and Young People's Learning
Disability Liaison Nurse

x3436 (01603 287436) Fiona.springall@nnuh.nhs.uk

Nic - Lead Learning Disability Liaison Nurse x3862 (01603 287862) Nic.smith@nnuh.nhs.uk



### What can this service offer to support patients, families/carers and staff?

- Aim to improve hospital experiences for children and young people with learning disabilities and/or Autism
  - Make the hospital more accessible to patients with learning disabilities and/or Autism
  - Provide advice, guidance and training to staff about learning disabilities and Autism
    - Work alongside both inpatients and outpatients
- Provide outpatient support which may involve a home visit prior to attending NNUH
- Liaison with community providers, schools, other health professionals across the MDT
  - Development of health passports, care plans to support admission etc.
    - Provide accessible information/communication aids
    - Support patient's understanding of medical procedures
      - Support with transition to Adult services



Become a volunteer and support families of children and young people with special educational needs & disabilities (SEND)

## **CAN YOU...**

- Give information, advice and support
- Help with paperwork
- Explain procedures
- Support at meetings



Introduction day - 18th September 2019
Compulsory training days - 5th, 6th, 7th November 2019
Venue - Keystone Innovation Centre, Thetford, IP24 1JD
For more information and to book your place contact us or visit our website www.norfolksendpartnershipiass.org.uk

Norfolk SEND Partnership, 148 Woodside Road, Norwich, NR7 9QL sendpartnership.iass@norfolk.gov.uk www.norfolksendpartnershipiass.org.uk



**TO BOOK CALL US ON 01603 704070** 

# Report from the Children's Commissioner

Anne Longfield, the Children's Commissioner, has published a report about children with a learning disability, autism or both in England living in children's mental health wards.



The Commissioner's recommendations, summarised below, will strike a familiar note with many families whose children are in a less extreme situation, but still lacking the quality of care they require. The recommendations are:

# A cross Government plan to provide community support for children

'Accountability and scrutiny at a Ministerial level is vital to achieve real change, as successive reports and programmes have failed to deliver improvements.'

- The programme should have clear baselines and targets for what support is in place in each local area and where gaps exist, with a timetable for these to be filled.
- Better data should be collected on length of stay and delayed transfers of care in children's mental health hospitals.

## A new parent covenant to guarantee parental involvement

- Providers should sign up to a parent covenant to involve families in a child's care.
- Children and their families should be closely involved in the development of the strategy.

# There should be new funding for the right support in the community to enable children to stay with their families.

• A new national strategy should include a programme of support and an 'invest to save' fund to encourage locally commissioned community services, supported by a learning

network to share best practice.

- The Care, Education and Treatment Review process should be strengthened.
- At a regional level, NHS England should work with local commissioners to reduce length of stay and reduce the risk of admission. Local authorities need to maintain and make proper use of risk registers to identify these children and provide the right local support.

### Training on LD and autism

- All NHS staff and education staff should have training on learning disabilities and autism to help spot children at risk and work together to make sure families are getting the right support.
- Commissioners who are planning and buying support need training to commission specialist services within the community, rather than the cheapest available provision.
- Inspectors need training to identify whether services are providing specialist support.

## A programme to ensure excellent care within hospitals

- The government must review quality standards and establish new mechanisms of accountability and oversight.
- Hospitals need to focus on recruitment of high quality staff with the right values and investing in face-to-face initial training and CPD.
- Improving care in hospitals also means increasing access to education and meaningful activities, increasing access to appropriate therapies and behaviour support, and supporting contact with families.
- Much more must be done to reduce the use of restrictive interventions, including better training for frontline staff and a greater focus on ensuring that children with communication difficulties can understand what is expected of them.

You can read the full report at <a href="https://www.childrenscommissioner.gov.uk/wp-content/uploads/2019/05/cco-far-less-than-they-deserve-may-2019.pdf">https://www.childrenscommissioner.gov.uk/wp-content/uploads/2019/05/cco-far-less-than-they-deserve-may-2019.pdf</a>





# Direct Payments Workshop

For Parents/Nominated persons of Children with Short Breaks Budgets who have a Direct Payment (DP)



Norfolk County Council is making the support services for people who have Direct Payments, better!



Please come to our workshops, so we can talk about how we are making Direct Payments better.



Tell us what you think and have a cup of tea or coffee!



#### Where & When?

Tuesday 11<sup>th</sup> June 2019

10.30 a.m. – 12.00 p.m.

The Priory Centre Priory Plain **Great Yarmouth** NR30 1NW

Friday 21<sup>st</sup> June 2019

10:30 a.m – 12:00p.m.

The Willow Centre
Norwich
NR4 7JJ

To book your place please

email:



DPSSFeedback@norfolk.gov.uk

Or

Text/Call **07768803285** & leave a message with your name and venue choice.



## Family Voice Norfolk newsletter deadlines

The next newsletter will appear at the end of June. If there are issues that you would like to see covered, please email <a href="mailto:comms@familyvoice.org.uk">comms@familyvoice.org.uk</a> or leave a message on 07535 895748 before 24 June 2019.