

In this issue:

- 1 Family Voice Norfolk steering group
- 2 Administration Assistant advertisement
- 2 Safeguarding Adults survey
- 3 Learning disability annual health checks
- 3 Family Voice Norfolk newsletter deadlines
- 4 Scope Independent Support
- 4 SEND e-Newsletter
- 5 Experiences of Mental Health Services Feedback Event **6 July 2018**

- 6 Norfolk Disability Pride
- 6 Carer's Passports
- 7 Communication information
- 7 Online learning for parent carers
- 7 Family Voice Conference 2019
- 8 Norfolk SEND Partnership new website
- 8 What is a parent carer forum?

If there are issues you'd like to see in future newsletters, contact admin@familyvoice.org.uk or 07535 895748.

Family Voice Norfolk steering group

The priorities, strategy and work plans for Family Voice Norfolk are set by a steering group, following the remit of our Constitution. The steering group meets monthly throughout the year. As usual, at the meeting following our AGM (see the May 2018 newsletter and Constitution, available on our website <https://www.familyvoice.org.uk>), we welcomed new members and allocated roles:



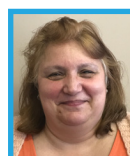
Chair
Tracey Sismey



Vice Chair and
Events Lead
Rachel Clarke



Treasurer
Alison Furniss



Representatives Lead
Lorraine Devere



Ambassadors Lead
Lisa Lonergan



Comms Lead
Nicola Baxter



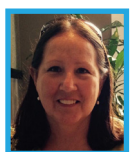
Safeguarding Lead
Claire Jack



Conference Lead
Natasha Oakley-White



Policies Lead
Wayne Doman



Administration Lead
Caroline Karimi-Ghovanlou



Kate Draycott
Membership Secretary



Bernadette Pallister
Administration Manager

Steering group membership and roles are voluntary, but we also have two members of staff who make key contributions to steering group meetings.

Are you looking for
some part-time,
family-friendly
work?

See page 2 of this
newsletter for
information about
our new post of
Administration
Assistant.



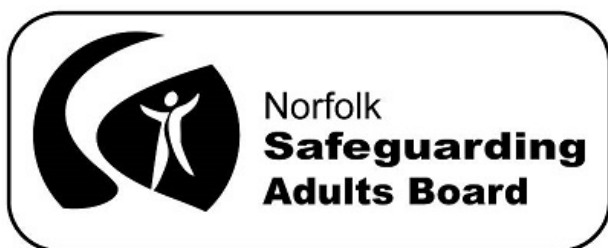
Administration Assistant working from home for 10 to 15 hours / week – flexible working (self-employed)



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. They must have good interpersonal skills, excellent communication and organisational skills, and be able to empathise with and understand the issues facing families of children with SEND. It is essential that they are able 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.

Applicants are invited to email a CV and covering letter, including details of two referees, to admin@familyvoice.org.uk by **Monday 16 July**. Interviews will be on Monday 23 or Tuesday 24 July. Further details can be supplied on request. A full job description can also be found on the Family Voice Norfolk website: www.familyvoice.org.uk



Norfolk County Council is carrying out a survey on behalf of the Norfolk Safeguarding Adults Board. It's relevant to any of our members caring for young people between the ages of 18 and 25 (and also, of course, if you also have care of older adults among your family and friends). You can find the survey at <https://www.smartsurvey.co.uk/s/5XOID/>

The Norfolk Safeguarding Adults Board will use this survey to find out more about what people in Norfolk understand about safeguarding adults at risk of abuse and neglect. The aim is to use this knowledge to get the right information

and messages to the right people to help make Norfolk a safer place to live.

You can choose not to take the survey, to stop responding at any time, or to skip any personal questions that you do not want to answer. The online survey will take approximately 5–10 minutes. Your responses to questions will be recorded once you move on to the next page.

Your responses will be confidential and no identifying information such as your name, email address or IP address will be collected. All data is stored in a password-protected electronic format.

The anonymised results from this survey will be shared with members of the Norfolk Safeguarding Adults Board.

If you have any questions about this survey, please contact Andrea Smith at andrea.smith@norfolk.gov.uk or on 01603 223085.



Learning disability annual health checks

From the age of 14, people with a learning disability should be invited by their GP for an annual health check. If an invitation doesn't come, it may be because your young person is not on the GP's learning disability register. You can ask for this to be checked and request a learning disability annual health check at the same time. Make sure you are noted as a carer, as well.



By beginning these checks as soon as they are available:

- a young person becomes used to knowing what to expect
- families can help both health staff and the young person to know how best to communicate and make the most of the appointment
- health staff can make sure that appointments for the young person are always long enough
- sometimes health or behavioural issues are assumed to be part of the learning disability but in fact have a physical cause. An annual check helps to spot this.
- systems for health checks are already in place for later years when the young person may be living independently or with other support.
- young people are helped to understand that we can all do things to improve our health and can feel empowered to take responsibility as far as is appropriate for them.

In addition, annual health checks mean that the GP has up-to-date information should you need him or her to give a report or sign a certificate for DLA, PIP or ESA.

Mark Gower, Designated Clinical Officer (DCO) for Norfolk, gave a workshop at the Family Voice Conference this year about 'Health Transition', which outlines what is important for 14–25-year-olds with special educational needs and/or disabilities (SEND). You can find the slides from his talk on our website at <https://www.familyvoice.org.uk/articles-reports/conferences/>

Mencap have a national campaign on the subject called 'Don't miss out', which also has materials you can share with young people themselves: https://www.mencap.org.uk/advice-and-support/health/dont-miss-out?utm_source=twitter&utm_medium=social

Family Voice Norfolk newsletter deadlines

The next newsletter will appear in August and cover both July and August. We aim to publish ten newsletters a year, so November/December and July/August both cover two months. If there are issues that you would like to see covered in the next newsletter, please email admin@familyvoice.org.uk or leave a message on 07535 895748 **before the end of July 2018**.

We want the newsletter to be as useful and accessible as possible. Please don't hesitate to get in touch in the same way if you have suggestions for subjects we should cover or improvements to how they are presented. For example, our Membership Secretary asked for page numbers, so it was easier to put printed-out pages in the right order. As you'll see below, they have appeared!



Independent Support Norfolk

Scope will be closing its Independent Support services in Norfolk and other areas on 31 July 2018. This is because the funding for these services is coming to an end at that point. The services have been funded by the Council for Disabled Children (CDC) in line with their contract to deliver

a nationwide programme of independent support to families and young people who require an Education, Health and Care Plan (EHCP).

The CDC has now decided not to issue new contracts to continue Independent Support and instead will be offering grant funding directly to local authorities.

If your annual review at the service is scheduled before 31 July, Scope will carry it out as normal. From August 2018 onwards, parents, children and young people will continue to be able to access information, advice and support on statutory assessment and annual reviews from their local Special Educational Needs and Disabilities Information Advice and Support Service (SENDIASS) <https://www.norfolksendpartnershiassi.org.uk>

If you have any questions or queries, you can contact Toby Greaves, National Delivery Manager, by phone on 07436 810611 or by email at toby.greaves@scope.org.uk. For any information about other similar services in your area, you can also contact Scope's helpline at 0808 800 3333.

SEND e-Newsletter

If you don't already subscribe to Norfolk's SEND e-Newsletter, you can do so easily at www.norfolk.gov.uk/send – the Local Offer website.

If you have previously received the newsletter, check that you responded to an email from NCC asking for your permission to retain and use your contact details near the GDPR deadline. If, like many of us, you ignored this (and many similar emails), respond now or subscribe again, or you may not receive the SEND e-Newsletter in future.

The newsletter is full of information about events and services in Norfolk that may be of interest to you and your family.

Remember...

If you have news or views to share with us, you can contact our Membership Secretary Kate on 07950 302937 or email her at membership@familyvoice.org.uk or contact us on:



www.familyvoice.org.uk



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



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

★ Please note: the date for this event is very near the beginning of July. Book now if you are interested. ★



Experiences of Mental Health Services for Children, Young People and Families Feedback Event

Friday 6th July 2018

10:00 – 14:00 including lunch (provided)

The Kings Centre, 63 – 75 Kings Street, Norwich, NR1 1PH

Norfolk and Suffolk NHS Foundation Trust (NSFT) are working with Carer's Matter Norfolk, Family Voice and Norfolk Family Carer's to provide opportunities for parents and carers to feedback their experiences of mental health services.

These meetings will be your chance to help shape the future of the Trust and to help us better engage with and involve service users and carers in sustaining improvements throughout 2018 and beyond.

We would like to invite any parent/carer whose child or young person aged 0-25 is using or has used (in the last 12 months) NSFT services. This includes services such as Wellbeing, ADHD, ASD, Eating Disorders, Early Intervention in Psychosis, Integrated Delivery Teams (IDTs), Child, Family and Young Person, Under 14 (CAMHS) and any other service provided by NSFT.

This event is also open to support groups or voluntary organisations who are involved with children, young people and families in the area.



To register for this event please contact:

Dawn Edwards

Dawn.edwards@nsft.nhs.uk Tel: 01603 421414





16 September 2018
The Forum, Norwich
10:00am – 4:00pm

Equal Lives, The Forum, Norwich City Council, Norfolk County Council and the University of East Anglia are joining forces, alongside many local businesses and groups, to present a celebration of disabled people and the diversity of our community. Everyone is welcome.

The day, and events either side of it, will showcase local artists, performers and speakers, highlighting skills and abilities of disabled people and challenging negative stereotypes. There will be a marketplace aiming to bring together individuals, groups and businesses to engage with disabled people, opening up conversations and opportunities to develop inclusive services and activities.

You can find out about the day's events at <https://equallives.org.uk/get-involved/disability-pride/disability-pride-whats-happening-on-the-day/>

Carer's Passports

The Norfolk and Norwich University Hospital has a Carer's Passport scheme, which supports carers who are visiting and caring for patients staying in hospital.

The Carer's Passport is available on all adult inpatient wards with the issuing of the passport at the discretion of the nurse in charge. It offers some concessions as a small gesture of thanks and appreciation, which include discounted meals in the main restaurant and the coffee shops run by the West and East Outpatient areas as well as free parking.

The Carer's Passport is for unpaid carers of any age who are willing to provide aspects of care while a patient is in hospital. Aspects of care could include emotional and psychological support to maintain health and wellbeing, personal care and assisting at mealtimes.

In alignment with the Carer's Passport, the Carer's Partnership Agreement Form will be available for ward staff to use when issuing the passport. The form sets out the agreement between the carer and the ward about what

the carer can offer in terms of support for the patient while they are in hospital.

Our Vision
To provide every patient
with the care we want
for those we love the most

Norfolk and Norwich University Hospitals
NHS Foundation Trust

Carer's Passport

Carer's Passports are for unpaid carers of any age who are willing to provide aspects of care while a patient is in our hospital.

Aspects of care could include:

- Emotional and psychological support to maintain health and wellbeing
- Personal care e.g. meeting hygiene needs
- Assisting at mealtimes

*Issuing of the passport is at the discretion of the nurse in charge



Communication information



You may remember that the plan is to continuously update and improve the SEN Support Guidance Document that has been produced by the local authority to give mainstream schools and parents information about what provision the LA expects to be made available to pupils of all ages at SEN Support level – i.e. without the need for an Education, Health and Care Plan (EHCP). The whole document is available to read or download on the Local Offer at <https://www.norfolk.gov.uk/children-and-families/send-local-offer/education-and-training-0-25/special-educational-provision-we-expect>

Family Voice Norfolk represented parent carers alongside other interested parties at a recent meeting to begin this work, and the first section to be revisited was the one entitled Communication and Interaction: Speech, Language and Communication Needs.

In the course of the meeting, some resources were recommended that parents might find useful and that will be referenced in the revised Guidance. They can be downloaded from the Communication Trust website at <https://www.thecommunicationtrust.org.uk/resources/resources-for-practitioners/universally-speaking.aspx>

The resources are called *Universally Speaking* and consist of a series of booklets that show where children should be with their communication skills at any given age, what helps them to learn to talk and listen and what to do if you have concerns about any of their communication abilities.

The website also has other downloadable resources for parents that may be of interest.

Online learning for parent carers

The Carers Matter Norfolk website (<https://carersmatternorfolkelearning.org.uk>) now has an eLearning Portal for unpaid carers. It brings together, in one place, online learning to support carers to manage the practical and emotional aspects of caring, as well as their own health and wellbeing. This includes material for parent carers.

The design of the eLearning Portal, from the background to the categories and topics, was led by what matters to carers. If you find the ePortal useful, or if you have comments to make, please do give feedback to Carers Matter by means of the button on the right. This will help to make future materials even more useful to carers.



Carers Matter Norfolk

It's never too early to save the date...

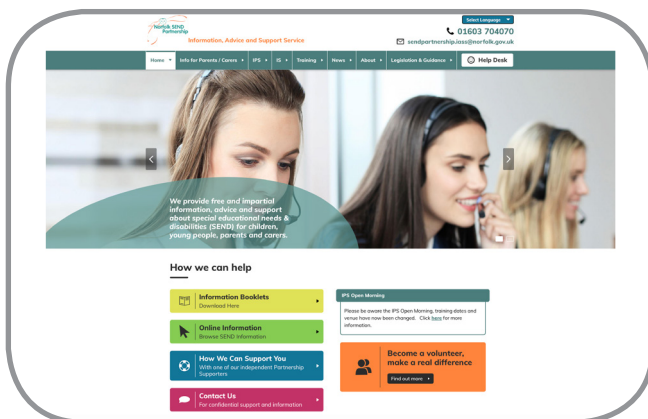


Family Voice Norfolk Ninth Annual Conference
Saturday, 16 March 2019



John Innes Centre, Norwich NR4 7UH





Norfolk SEND Partnership new website

Like Family Voice Norfolk, Norfolk SEND Partnership has recently launched its new website. Visit it at <https://www.norfolksendpartnershiass.org.uk> Norfolk SEND Partnership provides free and impartial information, advice and support about special educational needs and disabilities (SEND) for children, young people, parents and carers.

What is a parent carer forum (PCF)?

We are! Parent carer forums are groups of parents and carers of children and young people with special educational needs and/or disabilities (SEND). They work with local authorities, education settings, health and social care providers to make sure that the planning and provision of services for families takes full account of parent carer views and experiences, so that those services can be effective, timely and the best use of resources.

Almost all local authority areas in England have a parent carer forum – over 150 in all. In Norfolk, this is **Family Voice Norfolk**. It has been funded by grants from the Department for Education and the local authority, but works independently to improve the lives of children and young people with SEND and their families.

In 2018, for the first time, as well as DfE and LA funding, we have secured some funding from the five Clinical Commissioning Groups (CCGs) in Norfolk. This is important, as we have worked with Health colleagues for many years and are increasingly being asked to do so. All of us want 'joined up' services for our children and young people, who may well need to access both specialist healthcare and special educational provision. For services generally and Education, Health and Care Plans (EHCPs) in particular to work as well as possible, Education, Social Care and Health services need to work together.

Family Voice Norfolk encourages all parent carers of children and young people with SEND to become members. It seeks to gather and understand the experiences and views of families in many ways. This knowledge is then used to inform work with providers and decision-makers.

By far the most effective way of working is by means of **co-production**, where planners, providers and parent carers work in partnership to create the best outcomes possible.

Family Voice Norfolk is part of the **National Network of Parent Carer Forums** (NNPCF), which means that it is also able to ensure that the voices of Norfolk parent carers reach decision-makers in national government. In recent weeks, the steering group of NNPCF has had face-to-face meetings with Minister of State for Health Caroline Dinenage, Disabilities Minister Sarah Newton and Minister for Children and Families Nadhim Zahawi, raising issues from PCFs across the country. The experiences and concerns of families of children and young people with SEND nationally are more often than not remarkably similar, and cumulatively give a powerful message to the government. Find out more about NNPCF and subscribe to their newsletter at www.nnpcf.org.uk