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

## *Don't miss these June dates...*



Are you the parent of a child or young person with special educational needs and/or disabilities (SEND)?

Do you want to find out about  
**PREPARING FOR ADULT LIFE?**



Join us for coffee at one of our information and feedback sessions to talk about **TRANSITION** and what it means for your family.

We've invited Frank Crowdy, Transition Lead for Norfolk County Council, to tell you about the **NEW TRANSITION SERVICE**. A representative of the Local Offer will be there to help you navigate existing information and improve it for the future.

- Ask questions about what transition could mean in your family.
- Find out who can help and advise you.
- Make sure NCC knows what most concerns families like yours.
- Share ideas with other parent carers.

**NEW!**  
extra info  
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**Tuesday 5 June 2018**

10.30am – 12.30pm  
Ayton House, 11–17 Ayton Road, **Wymondham**, NR18 0QQ

**Tuesday 19 June 2018**

10.30am – 12.30pm  
Community Room, South Lynn Community Centre,  
10 St Michael's Road, **King's Lynn**, PE30 5HE

**Thursday 21 June 2018**

10.30am – 12.30pm  
Charles Burrell Centre, Staniforth Road, **Thetford**, IP24 3LH

**Thursday 28 June 2018**

10.30am – 12.30pm  
Atrium, Spenser Avenue, **North Walsham**, NR28 9HZ

If you can come, please email us at [events@familyvoice.org.uk](mailto:events@familyvoice.org.uk) or call/text on 07535 895748.



## Family Voice Norfolk Conference 2018: report

With over 40 stands, 15 'speed-daters' and 10 workshops, Family Voice Norfolk's eighth annual Conference for parents and carers of children with special educational needs and/or disabilities (SEND) was our largest ever. As usual it was held at the John Innes Centre and more than 300 people attended. Our Conference has become an important event for parent carers and this was highlighted by Wally Webb, who came along to feature the Conference on Radio Norfolk just before the start. The keynote speaker, Jonathan Stanley, gave a presentation on redesigning the mental health system for children and young people in Norfolk. Child and Adolescent Mental Health Services (CAMHS) is a hot topic nationally and has been under a great deal of scrutiny in Norfolk, so it was fitting that we gave it centre stage at this Conference, both through Jonathan's presentation and our workshops.



As usual, following the keynote speech, the first five workshops took place, co-hosted by a member of Family Voice and a speaker from the local authority or health services or a service provider, service manager or commissioner. These covered Personalised Travel Payments (PTPs), Education, Health and Care Plans (EHCPs), Preparing for Adult Life (the most popular workshop), Health Services identifying Pre-School Age Children to Norfolk County Council, and Speech and Language

Therapy services. The last is under review currently by Norfolk County Council and has been raised as a concern by many parents. The provider, East Coast Community Healthcare, gave a well-received presentation and fielded questions from parents.

In the afternoon sessions, there were workshops on Independent Travel Training, Health Transition and Annual Health Checks, the Children and Young People section of the Local Offer, Carers Matter – What Matters to You?, and Questions and Answers on CAMHS. All the presenters were very knowledgeable and engaged, which was appreciated by parents. Two

hundred people attended the workshops and most of the presentations are available on our website at [www.familyvoice.org.uk/articles-reports/conferences/](http://www.familyvoice.org.uk/articles-reports/conferences/) If you would like hard copies of any of the materials from individual workshops, please email [admin@familyvoice.org.uk](mailto:admin@familyvoice.org.uk) or write to Family Voice at Family Voice (Norfolk), PO Box 1290, Long Stratton, Norwich NR15 2HD.

Since we were able to expand into an additional area of the conference complex, we increased the number of stands compared with previous years. There were sports charities, many local and national SEND charities, healthcare organisations, services from the local authority, educational organisations, care homes and many others represented.

"Great conference – don't feel so alone..."



A one-stop shop for information & people of whom you can ask...

During the lunch break, the ever popular and always oversubscribed event – ‘speed-dating’ with a professional from health services or the local authority – was held. This allowed individual carers to have a short one-to-one session to get their questions answered. This year we managed to fit 15 into the auditorium to answer all your questions. Throughout the Conference, we also had our own information available at the Family Voice stand.

This year our children with SEND were looked after by The Clare School, Norwich, with help from staff from other special schools and from providers. Although the school is a short drive from the conference centre, it allowed us to look after more children, including those with a wider range of needs than previously.

There is so much to take in and so little time!

There was much positive feedback about the childcare. It was fortunate that we chose this venue as, just a few weeks before the Conference was held, part of the facility we normally use was damaged by bad weather. This meant we couldn't use that area for extra stands and had to double up in an area also used for workshops – not an ideal situation as some of your feedback noted!

As always, we invited feedback from every participant, whether parent carer, professional or practitioner. You provided comments on what you found most useful about the event, what could have been better, and many other issues. We were also able to get your updates on the reviews we have carried out over the last year. Half of the individual parent carers attending and many stand holders gave us their responses and we should like to thank you all.

Of the parent carers who responded, 90% said they would definitely recommend our Conference to a friend and we were given an overall satisfaction rating of 95% from parent carers for their Conference experience. Next year we will aim to make it 100%!

Thank you, Family Voice, for bringing this conference together...





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

## Family Voice Norfolk Ninth Annual Conference Saturday, 16 March 2019

### Family Voice Norfolk AGM 2018: report

The Family Voice Norfolk AGM was held on 15 May at Ayton House, Wymondham. We were delighted to welcome so many members and representatives of other groups involved in special educational needs and/or disability (SEND).

Kevin Vaughan, Service Manager of Carers Matter Norfolk, gave a short talk on how his organisation and partners can offer support to carers and ensure that issues of concern to carers are voiced where changes can be made. Carers Matter's remit has been to support carers over the age of 16 who are caring for someone over the age of 18. As many Family Voice members will know, funding for and recognition of parent carers of those under 16 still leaves much to be desired. Kevin brought the good news that his organisation is now also able to support families with young carers under 16. This means that many families where children and young people have caring siblings can now also be supported. It was good to hear that Kevin continues to argue that support for all carers is essential. For more information about Carers Matter, see [www.familyvoice.org.uk/articles-reports/conferences/](http://www.familyvoice.org.uk/articles-reports/conferences/) where Kevin's slides from the workshop he gave at this year's Conference can be found, or go to [www.carersmatternorfolk.org.uk](http://www.carersmatternorfolk.org.uk)



In addition to the Chair's and Treasurer's reports, AGM documents showed the increasingly wide range of meetings and events at which Family Voice representatives speak on behalf of families. All AGM papers and more information about parent participation can be found on our website at [www.familyvoice.org.uk/articles-reports/agms/](http://www.familyvoice.org.uk/articles-reports/agms/)





## Goodbye to...

Trevor Wang, until recently our Treasurer, Conference Organiser and Administration Lead, whose help was invaluable in so many areas of Family Voice. He wrote the Conference report in

this issue of the newsletter and led the project to create a new Family Voice Norfolk website, introduced below.

Trevor stepped down from the steering group at the AGM, as all of us do when our youngest child with special educational needs and/or disabilities passes the age of 25.

We would like to wish Trevor a happy 'retirement' from Family Voice and thank him again for all his hard work and clear-sighted guidance.

## Family Voice Norfolk website

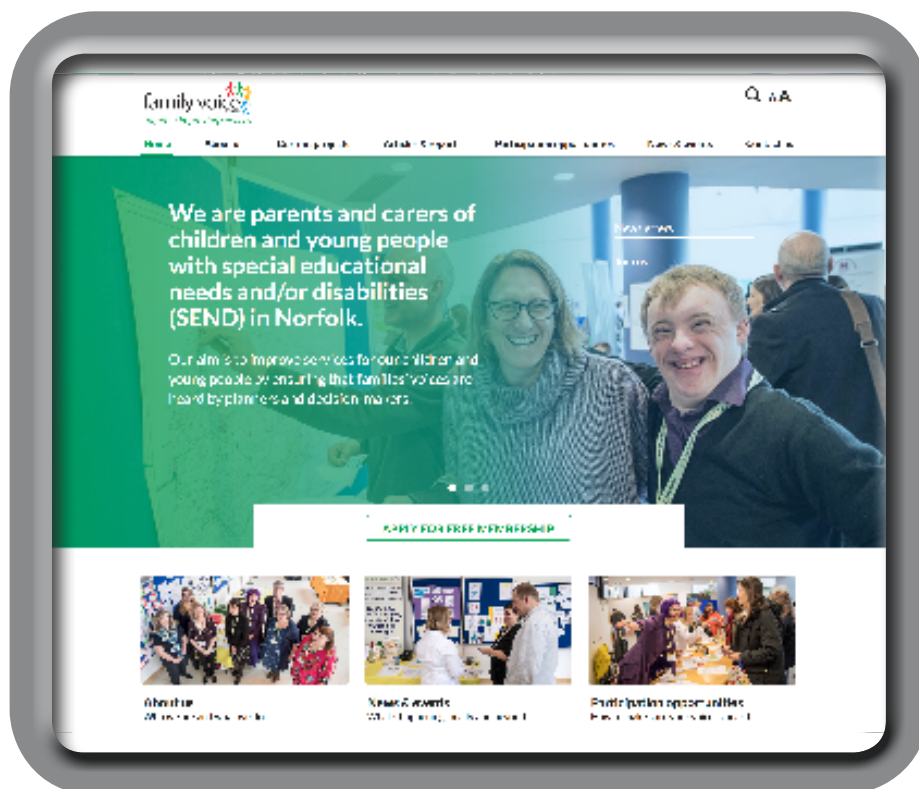
Increasingly, we and our members are accessing most of our information about SEND and local initiatives online. It is important to us that our communication with members is as clear and direct as possible. Readers of this newsletter will know that we have been working on a new website since last year. With funding acquired, Trevor was determined to leave us with a website we could easily update and confidently recommend.

After investigation and tendering, Jason Hubbard of JMJ Web Design was chosen to create the new site. He proved to be an excellent choice, quickly understanding our needs and building a site that is easy to use and flexible enough for future development.

We are still at the stage of adding basic content, but already are delighted to find that this is straightforward and will enable us to keep our members informed about our work as well as wider issues. You will also be able to join us, give feedback and book events online.

Please do go to [www.familyvoice.org.uk](http://www.familyvoice.org.uk) and explore. As always, we welcome your views and look forward to being able to reflect your wishes and experiences more fully than ever. There are lots of opportunities to contact us on the website if you want to make suggestions for content or find any of it hard to navigate. We are always keen to hear of any way in which we can improve contact with you and make it easier for you to let us know what you think.

And we're as keen as ever to add photos and drawings from our member families...





# family voice family chat ... urgent announcement

NEW!  
extra info  
re: King's Lynn  
date

Family Voice's event Transition to Adult Life on Tuesday, 19 June 2018 in King's Lynn now extends into the afternoon. From 1pm, Norfolk and Suffolk NHS Foundation Trust (NSFT) will be presenting on **mental health services** in West Norfolk for children and young people and would really like to hear about your views and experiences. Does your family access mental health services provided in West Norfolk (Thurlow House)? Are you trying to access the services, on a waiting list for services or just needing to know what is available? Come along and share your views and help to shape the future of such services for our children and young people.

Come in the morning and stay for both sessions (light lunch provided) or simply come to the

session that best fits your needs. It's entirely up to you. All we ask is that you register for the session(s) with Bernadette, our Admin Manager, on [admin@familyvoice.org.uk](mailto:admin@familyvoice.org.uk) or 07535 895748.

The event is from 10.30am to 12.30pm for the Transition session and from 1.00pm for the NSFT mental health session at:

**Community Room, South Lynn  
Community Centre, 10 St Michael's Road,  
King's Lynn, PE30 5HE**

The Community Centre is easily accessible from the A47 for anyone coming by car and there is plentiful on-site parking.

We look forward to seeing you in King's Lynn and hearing about services in the area.



## Could you be an ambassador?

Rachel Clarke, Ambassadors Lead, asks:

Do you live in **North Norfolk**? Do you live in **Norwich**? Are you passionate about Family Voice Norfolk? Do you enjoy chatting to other parent carers and attending events? Are you looking for some interesting, paid, part-time work that you can fit around your family?

We are looking for new ambassadors to join our team. The role involves promoting our annual Conference and new Family Voice, Family Chat sessions, building relationships with educational settings, talking to parent carers about Family Voice Norfolk's role, increasing our membership numbers and hearing about families' experiences of services and provision within Norfolk. Hours are flexible and family friendly because we are all parent carers on the ambassadors team.

Interested? Like to know more? Please contact Bernadette, our Admin Manager, on [admin@familyvoice.org.uk](mailto:admin@familyvoice.org.uk) or 07535 895748 for an initial chat.

## 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 [admin@familyvoice.org.uk](mailto:admin@familyvoice.org.uk) or leave a message on 07535 895748 before 24 June 2018.





## Carers Week 2018

Carers Week is an annual campaign to raise awareness of caring, highlight the challenges carers face and recognise the contribution they

make to families and communities throughout the UK. Carers Week 2018 is from **Monday 11 to Sunday 17 June 2018**. We asked you for your own experiences of being a carer...

This family chose to give each member a voice:

Being mum and carer is very full-on. I do everything a mum would but also so many 'extras' that I imagine other mums and dads don't have to. It's hard to ask for help or to admit that it does get too much at times. Sleep is a rare luxury, even after all this time, and I never wake on my terms, I am always woken. I feel like I live on my nerves because of the unpredictability and have to risk assess everything we do. There is an overwhelming sense of love and also of fear, of not getting it right, of not having enough in place for the future. Mostly, however, I look at my child, at my children and at my husband and think, we do our best, there are more smiles, fun and laughter in our house than there is sadness and so we must be doing alright. And for exhaustion ... that's the reason caffeine was discovered.  
(Mum, 'ancient', to quote my children)

I am dad and carer. I worry about creating an imbalance, spending more time and attention on our SEND child than on our other two, not through choice but through need. For me, I have to look at everything through the lens of autism, to try to interpret and navigate for him. It can be amusing and exhausting. (Dad, getting on!)

We have to do more stuff to look after him. Being careful with him on the road and keeping him safe in shops because he goes off and talks to everyone. At theme parks we get to skip the queue because of him. (Brother, 11)

It can be hard at times because it is stressful. I have to give him space but have to keep him safe. It can be funny at times. I go to a young carers group. (Brother, 13)

My family members are also my carers. We go out. They help me to get dressed, with toileting because I have anxiety issues, keep me safe and happy. I give them 10/10! (I'm 15.)

Sometimes being a carer can feel overwhelming:

I'm a parent carer of two young people with special needs. For years, I didn't want to think of myself as a 'carer'. I wanted my family to feel as 'normal' as it could, because that was what I believed – that having a disability or learning difficulties was part of life. We were just a family. I was just a mum. When my children became young adults, I had to face the fact that I was more than a mum now – and I guess I always have been. I am the person who helps them negotiate the outside world, which, despite all my efforts, doesn't seem to understand us. Somewhere along the way, too, I've lost who I thought I was. It is so hard to ask for help. Asking for help for my children – feeling that I'm the only person who can do so and who cares – makes me feel desperate. When all they needed was warmth and food and cuddles, I felt confident I could give them everything. Now the stakes seem so much higher and I'm scared. I'm glad parent carers have a voice through Family Voice and other organisations. I'd love it to be louder.



## Consultation on elective home education

On 10 April 2018, the Department for Education published a consultation on elective home education. The consultation is in two parts. The first one is a call for evidence, covering issues such as the registration of children educated at home, monitoring of home education provision and support for home providers. The second part is seeking comments on draft versions of two DfE guidance documents, one is targeted at local authorities and the other for **parents**.

Among the points that may be of particular interest in relation to SEN are:

- Reports of schools encouraging parents to home educate as a response to behavioural or attendance issues

- The process for a parent wanting to move their a child out of a special school and into home education
- Guidance to local authorities and parents about particular issues that arise if a child being home educated has SEN, complementing the material in the SEND Code of Practice.

The DfE would welcome your response to the consultation – particularly in relation to children and young people with special educational needs and disability (**SEND**) who are **home educated**.

Both parts of the consultation can be found at this link: <https://www.gov.uk/government/consultations/home-education-call-for-evidence-and-revised-dfe-guidance>

## Special Educational Needs and Disabilities Schools' Workforce

The DfE's new SEND Schools' Workforce contract aims to bring together schools, condition-specialist organisations and SEND focused school improvement experts to help equip schools to deliver high-quality teaching that supports children with all types of SEND. Eight Regional Schools' Commissioners (RSCs) based in eight regional hubs will work to encourage schools to prioritise SEND in terms of school improvement. Read more at <http://wholeschoolsend.com/>

## 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](mailto:membership@familyvoice.org.uk) or contact us on:



[www.familyvoice.org.uk](http://www.familyvoice.org.uk)



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



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

## SEND e-Newsletter

If you do not already subscribe to Norfolk's SEND e-Newsletter, you can do so easily on the Local Offer website ([www.norfolk.gov.uk/send](http://www.norfolk.gov.uk/send)).

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





HEALTHWATCH NORFOLK

# AGM

24 JULY 2018 THE FORUM NORWICH

Tue 24 July 2018    The Forum, 2 Millennium  
09:30 – 15:00 BST    Plain, Norwich NR2 1TF

This year's AGM features a drama performance by Acting Out Productions who will perform a live drama to highlight mental health issues. Healthwatch Norfolk will take a look back at the work they have carried out over the last year and celebrate their Chair, William Armstrong, as he steps down from his role. Upstairs in the main atrium, Healthwatch Norfolk will be joined by a number of organisations who will be sharing information with the general public, alongside a café area providing light refreshments.

A link to the event can be found at <https://www.eventbrite.co.uk/e/healthwatch-norfolk-annual-general-meeting-showcase-tickets-45231001142?aff=ehomecard>

## Supported Internships Project

Norfolk County Council has secured £107,000 from the Department for Education as part of the 'Preparing for Adulthood' initiative to increase pathways into employment for young people with special educational needs and/or disabilities (SEND).

The Supported Internships Project will bring together representatives from across the county including the local authority, employers, education and training providers, parents and carers, young people with SEND and employment groups. This forum will have direct involvement in supporting and sustaining work for young people with SEND – providing training for job coaches and creating 20 Supported Internships within local businesses.

As well as guiding young people in the workplace, the Job Coaches will help employers to establish a sustainable employment package so that the skills of young people who have SEND are recognised and valued.

Representatives of Family Voice Norfolk met Sarah Jennings, the Project Co-ordinator, to share some of the issues that parents and young people with SEND experience when seeking employment. She is keen to hear from anyone who has an interest in the subject and can be contacted at [sarah.jennings@norfolk.gov.uk](mailto:sarah.jennings@norfolk.gov.uk)

## Carer's Emergency Card

If you are caring for someone, a Carer's Emergency Card can help to ensure that that person will be safe if you are caught up in an emergency. Simply go to <https://www.norfolk.gov.uk/care-support-and-health/care-and-support/urgent-help/carers-emergency-card>

It takes only a few minutes to fill in the online form. A card will be sent to you that you should carry with you. If you are involved

in an accident or are suddenly taken ill, the emergency services will recognise that you are a carer and be able to access the plan you have made, contact your named friends or family, or take action themselves if that's not possible.



# Central Norfolk Wheelchair Personal Health Budget Project Update and Co-production Workshop

NHS services in Norwich, South Norfolk and North Norfolk have been working with people who use wheelchair services and with carers and community organisations, to develop a new Personal Health Budget approach to wheelchair provision in central Norfolk. Join us at this celebratory and interactive workshop to find out more about recent changes, hear about a new Pilot, and help to co-produce the future of this work.



## Who should attend?

All are welcome.

We are very keen to involve Wheelchair Services customers; health and social care professionals and leaders; user groups and forums; and the voluntary and wider community sector.

Natalie introduces recent Norfolk wheelchair co-production outputs to a second event - March 2018  
*[Graphic and image by Pen Mendonca, [www.penmendonca.com](http://www.penmendonca.com)]*

**Find out more and get involved in the next phase of this work**

**When:** Tuesday 26 June, from 9.30am for a 10am start. 12.30pm finish.

**Where:** The Costessey Centre,  
Jerningham Room, Longwater  
Lane, Norwich, NR8 5AH

## How to Book?

To book your place please email Lea Littleford at Norwich Clinical Commissioning Group via: [lea.littleford@nhs.net](mailto:lea.littleford@nhs.net)

**NB: Please let us know if you have any special access or support requirements that we should be aware of when booking your place.**

