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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.

Remember...

At Family Voice we are always keen to hear from you with news or views about the services you are receiving or would like to receive.

We never share personal or identifying information but anonymise what you tell us and use it to affect decisions made by the education, social care and health authorities.

You may want to praise excellent services or tell us about more negative experiences. It is all useful information that means our representatives, who attend meetings and

boards, can speak authoritatively about the experiences of families like yours.

It's easy to tell us how things are for you:

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

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

Family Voice Norfolk newsletter deadlines

The next newsletter will appear at the end of February. 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 20 February 2019.



Happy New Year! Can we make this year better than the last?

We understand that our members' lives are already full – not just with everyday life but with all the anxiety, advocacy and uncertainty that all too often is part of raising a child or supporting a young adult with special educational needs and/or disability (SEND).

At Family Voice Norfolk we believe that the stress, conflict and isolation we sometimes experience **can** and **should** be reduced.

There are many examples in this newsletter of how vital it is that our voices are heard by the organisations that have such a huge impact on our children's and young people's lives, not to mention our own lives – the local authority, social services and health services. At a time when budgets are being cut and the uncertainty about the future that many of us feel mirrors the political uncertainty that currently exists nationally, it is more important than ever to ensure that some of the most vulnerable in our society have, with the help of their parents and carers, a real say in how they are supported.

You are the expert on what life is like for your family. Please help us ensure that those who make decisions that massively affect our lives understand what we and our children need. As we so often say: together we are stronger.

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.

If you have a few hours to spare during school hours and would like to know more, come to our:

Open Day

on 31 January 2019



drop in any time between 10.30am and 1.30pm



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 disability (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.



Changes to funding of adult social care – update

You may remember reading in the last newsletter about the local authority's consultation on its proposals to save money when calculating the contribution that adult recipients of social care may need to make to pay for their care. The consultation included some important proposals:

- young people should have a lower guaranteed income than older people (and therefore pay more for their social care)
- those on the enhanced rate for daily living PIP payments should use this to help pay for their care.

The consultation documents were supplied in an easy-read format, but the ideas they contain were complicated and the consultation document was 26 pages long. Many young adults with learning disabilities struggle to understand financial information and budgeting in their own lives and thinking about the implications of something that *may* happen is challenging for everyone. Family Voice urged parent carers to respond to the consultation on behalf of their young people and many of you, we know, did so.

However, the proposal was passed at the Adult Social Care Committee on 14 January. Many of our young people have already had personal budgets reduced in the past twelve months, with the expectation that they would pay for more of their needs from their Disability Living Allowance, Personal Independence Payment and/or Employment Support Allowance. Now more of these allowances are under threat.

One of the proposals that was passed was that young adults should have a lower MIG (minimum income guarantee) than older adults, yet their need for food, clothing, leisure, the ability to access their community, learn and develop is just as great if not greater than that of older adults. The difference is likely to be that

many of them are still living at home with parent carers and it is their families who are required to make up the shortfall in their living costs. For families already under pressure in caring and planning for a loved family member who may always need some degree of support, this is an added stress. It also makes many of us very frightened about the future of our young people when we are no longer around. If the services that are meant to protect and support them are in fact doing the opposite, who will stand up for them?

The proposals have to be passed now by two more committees, on 28 January and 11 February. Family Voice Norfolk will be sending a formal response to the Adult Social Care Committee's decision, pointing out the unfairness of targeting some of the most vulnerable people in our community, the real risks involved and the fact that although the local authority claims to work in co-production with parent carer forums and other representative bodies, Family Voice Norfolk was not involved in the discussions that led to these proposals.

The minutes of the meeting of 14 January were not available as we went to press, but the agenda of the meeting, which gives the results of the consultation many of you took part in, can be found [here](#), starting at page 137.

If you do not agree with what is being proposed, please consider:

- writing/emailing your local councillor
- writing/emailing your MP
- letting us know about your actions, emails, plans to protest etc. via our website or any of the other contact methods in this newsletter so that in our response we can truly reflect the level of concern that there is about these proposals among families.



Family Voice Norfolk Ninth Annual Conference

Saturday, 16 March 2019

John Innes Centre, Norwich NR4 7UH

Keynote speaker:

Sara Tough

Director of Children's Services

on her vision for Norfolk.

Booking is now open via a link on our Facebook page at

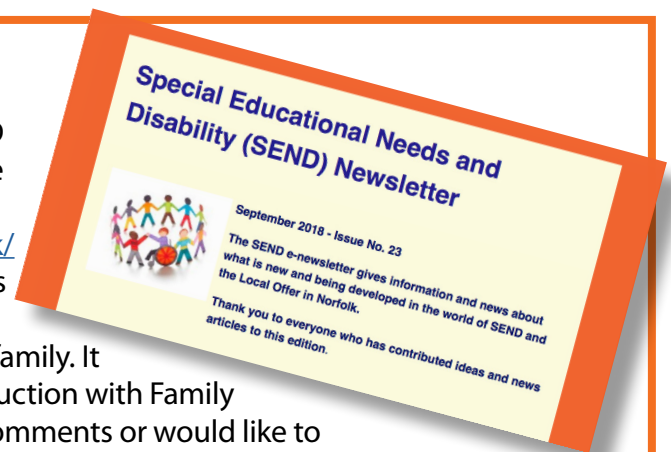
<https://www.facebook.com/FamilyVoiceNorfolk>

or via our website at <https://www.familyvoice.org.uk/posts/news-events/>

Places are always oversubscribed and each year we run a waiting list. On occasion we have had to turn people away only to find that others who had booked did not come. Please, if you find that you cannot attend after booking, let us know so that we can offer others the opportunity. We are already running a waiting list for those needing childcare for a child with SEND. As last year, The Clare School is running this for us at their own site.

SEND e-Newsletter

If you don't already subscribe to Norfolk's SEND e-Newsletter, or your subscription lapsed in the midst of the GDPR maelstrom, 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



Draft Adult Mental Health Strategy – consultation

The first draft of a Norfolk and Waveney strategy for adult mental health is now published. You can read it in full at <https://www.healthwatchnorfolk.co.uk/ingoodhealth/stp-mental-health/> This draft strategy was developed with input from thousands of local people and professionals, 95% of whom felt that services failed to meet the needs of the mentally ill. You can comment on the draft strategy at <https://www.smartsurvey.co.uk/s/NWMHStrategyDraft-Feedback/> until **Wednesday 6 February 2019**.



Direct Payment Support Services



NEW Direct Payments Support Services Workshop!



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!



Norfolk County Council

Where & When?

Thursday 14th February 2019
10.30 a.m. – 12.30 p.m.
Palm Court Hotel
North Drive
Great Yarmouth
NR30 1EG

February
14

Friday 15th February 2019
10.30 a.m. – 12.30 p.m.
Dereham Town Football Club
Aldiss Park
Norwich Road
Dereham
NR20 3PX

February
15

Thursday 28th February
11.00 a.m. – 1.00 p.m.
Swaffham Assembly Rooms
13 Market Place
Swaffham
PE37 7AB

February
28

To Book a Place?

Call:

01603 223392

or

Email:



DPSSFeedback@norfolk.gov.uk

Further workshops

Before Christmas, Family Voice members attended two workshops in Norwich about the new system, due to begin at the end of March, where Norfolk County Council plans to take support services for those receiving Direct Payments inhouse instead of these being handled by outside providers such as Equal Lives.

Further workshops in other parts of the county have now been announced (see left). Do go along if you can to find out about the proposed new system and give your perspective on issues that will be important to you.

Expert parent programme

The Council for Disabled Children has much useful information on its website at www.councilfordisabledchildren.org.uk/expertparent including handouts covering:

- Building a good relationship with your child's GP/Appointment top tips
- Health and wellbeing summary tool for planning appointments/interactions with health professionals

and e-learning modules that can be found at:

<https://councilfordisabledchildren.org.uk/learning/sections/parents/expert-parent-programme>

and include:



- The NHS structure and your child's rights within it
- Personal Health Budgets
- Making complaints and giving feedback
- Learning disabilities and behaviour that challenges
- National Deaf Children's Society Module

There are many other useful resources on the Council for Disabled Children website, as well as links to other organisations and publications.



Here is another opportunity to support families with children and young people with SEND. Of course, (see page 2) we would love you to first consider volunteering with Family Voice Norfolk, but we are a 'voice', representing, not supporting, so this is a different kind of opportunity. Many of us have had reason to be grateful for advice or support from the Norfolk SEND Partnership and we know that we share with many other groups (see page 7) a wish to work together to improve the lives of children, young people and their families, so we are happy to draw this to your attention.



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 - 28th February 2019

Compulsory training days - 30 April, 1 & 2 May 2019

For more information and to book your place contact us or visit our website

Norfolk SEND Partnership, 148 Woodside Road, Norwich, NR7 9QL

Email - sendpartnership.iass@norfolk.gov.uk

Website - www.norfolksendpartnershipiass.org.uk



TO BOOK CALL US ON 01603 704070



Together we are stronger

In November 2018, **Family Voice Norfolk** met with representatives of **SENsational Families**, **ASD Helping Hands**, **Norfolk SEN Network** and **Norfolk SEND Partnership** to share how we all work and how we can best work together. Mrunal Sisodia from the National Network of Parent Carer Forums facilitated the meeting.

There are over 15,000 children with SEN in Norfolk. Between the five groups, we estimate that we have active contact with approximately half of these children.

In discussion, it quickly became very evident that each organisation is hearing about similar issues affecting parents and their children and young people. The issues currently causing the most stress for families are:

- Education, Health and Care Plans (EHCPs)
- Tribunals
- Autism diagnosis

Representatives of these groups are keen to meet the Local Authority and Health services to discuss the contents of this report.

EHCPs

While there are instances where the EHCP process is working, most of the organisations were experiencing an increasing number of parents who were unhappy with part or all of the process, from trying to get a plan through to the finalised plan, and beyond that in its lack of implementation in educational settings. We are all hearing that:

- Parents are finding that it is taking too long for the EHCP to be written and finalised.
- There are cases where a final plan has been actioned without a draft.
- Some EHCPs are not fit for purpose.
- Workload for support in the EHCP process has doubled and trebled in recent years.
- Parents are finding that once an EHCP is in place, educational settings do not necessarily act on it.
- Parents feel that they have to have an EHCP to access services for their children and young people. The message that they may not need this is failing to reach them or being denied by educational settings.
- Higher numbers of parents are having to go to mediation and tribunal to have EHCPs that are fit for purpose and SMART.
- EHCPs are being done within the 'spirit of the law' not within the actual legal requirements of the law.

Tribunals

Norfolk SEN Network and Norfolk SEND Partnership are working to capacity on preparing parents for, in many cases, extremely complex tribunal processes. Between them, they have supported over 120 cases this year.

- Parents are resorting more and more to going through the tribunal process.
- Parents feel that the LA is forcing them down this route because it is cheaper than providing the services upfront, even if the LA loses the case at tribunal.
- Parents feel that the LA is forcing them down this route in the hope that they will give up.
- Some families report that these additional stresses have forced them into crisis and marital breakdown, which will have a knock-on effect on public services.

Contd on page 8



- Tribunal processes are long and demanding on support services such as Norfolk SEND Partnership and Norfolk SEN Network.
- Numbers of cases going to tribunal are increasing year on year.
- Nine out of ten cases do not make it to tribunal and are settled out of court.
- When cases do make it to tribunal, the majority are found in favour of the parent.

Autism diagnosis

ASD Helping Hands supports families throughout the diagnosis process with a variety of support groups, home visits and monthly clinics.

- Parents are finding that it can take three to four years to get a diagnosis for their child.
- Once the child has a diagnosis, there often is no on-going support

Recommendations

- EHCP co-ordinators to be adequately trained to understand and interpret the law around the EHCP process.
- Support organisations to be involved in the interview process of EHCP co-ordinators.
- LA and Health professionals to be held accountable for delays in the systems around EHCPs and diagnosis.
- Early intervention with parents to resolve issues that are currently being pushed through the tribunal process.
- Improved joint working between the LA and Health services to identify faster processes for ASD diagnosis and appropriate support thereafter.

It was helpful for everyone to gain an understanding of each organisation's remit and how we could each helpfully signpost parent carers to each other's organisations and others. We all feel strongly that families should receive the services and support that they need without feeling that these have to be 'fought' for.

If you haven't watched it before, take a couple of minutes to view this animation. You can view it by clicking on it below or find it on the home page of our website at <https://www.familyvoice.org.uk>

If readers are involved with or know of other organisations who would find it helpful to share information about working practices and how we can help each other, then please do contact Bernadette at office@familyvoice.org.uk or leave a message on 07535 895748.

