



Family Voice Norfolk Conference

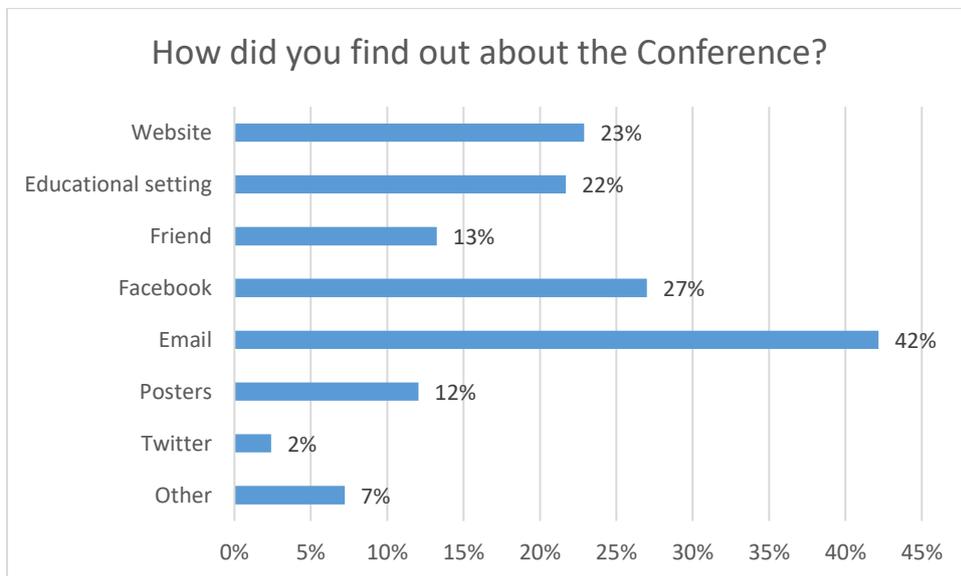
Saturday 16th March at the John Innes Centre

Appendix: Data and Feedback

The ninth Family Voice Conference was attended by 262 parent carers and 115 professionals from across Norfolk.

Each year we ask parent carers, presenters and stand holders for their feedback on our Conference and for updates on what is working and not working for parent carers at that time. We received 80 feedback forms from parent carers and a further 43 responses from presenters and stand holders. In the following sections are their responses. We have not edited these responses except if we feel that the information given may identify the person concerned or if specific individuals are named. It is always our policy to anonymise comments from families.

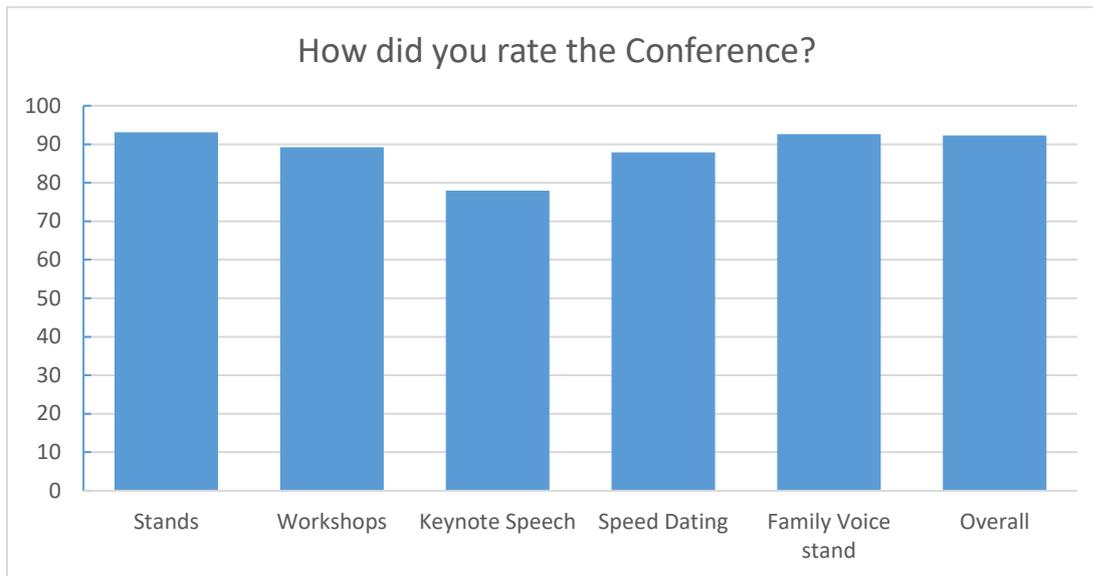
About the Conference



The ratings below are for the different activities at the conference in response to the following questions (score out of 100):

- How would you rate the stands at this event?
- How would you rate the workshops at this event?
- How would you rate the keynote speech at this event?
- How would you rate the speed dating opportunities at this event?

- How would you rate the Family Voice stand at this event?
- How would you rate your overall experience of this year's conference?



We asked you

What did you find most useful about this event?

- Sleep East, Family Voice, EHCP, Just one NHS, TITAN
- Various stands full of info / services
- EHCP
- I attended provision to be expected workshop. It was excellent. Very informative, gives me more confidence in approaching the school about my daughter's needs
- Finding out more about the services in the marketplace
- Faces to names and points of contact
- Being able to talk to people from various organisations who could give me support
- Being able to meet key people face to face. Autism advice service - fab personalised tips. Helpful advice on where to find support
- Chance to find out about different organisations and what support / help is on offer. To meet and speak with other parents, to meet professionals face to face and ask questions
- General talk and the Just One Norfolk workshop was great. Found useful information on sleep from Sleep East. People were very helpful and great.
- Finding out about services that I wouldn't have known existed and having the opportunity to speak with [professional] 1:1
- The stands and talking face to face
- Speed dating
- Workshops
- Transition info
- All of it
- Finding out about help for future years. Also about the Nature Nurture. Finding out about ADHD/ ADD info as youngest in waiting for diagnosis

- Stands, keynote speaker's talk
- It was all fantastic. So much information in a format accessible to all. The different formats - stands, workshops, guest speakers, speed dating - all help to keep the communication fresh
- Very informative. Workshops were useful
- Stands and information
- Everything - our first one so still lots to learn
- Huge array of stands and information - ATT, Sleep East, NANSA. Talk by keynote speaker - good to hear what is being planned. ASD pathway workshop. Speed dating with sleep specialist
- Names to faces
- The stands and keynote speaker
- The workshops - Preparing for Adult Life & EHCP
- Speed dating - very useful and signposted me to certain people and stands
- Preparing for Adulthood team
- Like-minded people in the same boat on the same journey. Having a wide selection of providers under one roof.
- To meet up with people that are in the same boat. To speak with people face to face
- Networking
- Meeting people who have similar experiences to talk to
- Loads of info
- Well-organised, good range of options - workshops, speed dating, stands. Good housekeeping - toilets, drinks, lunch, free car parking
- I found that it was very informative
- All professions in one place. Workshops. Being able to speak to people
- Booths, meeting other people, opportunities to volunteer
- Lots of information. Ability to talk to people who can answer. Speed dating
- Meeting various stalls with different services / options
- There is hope out there if you can access it
- General info
- Info helps with our journey
- Preparing for Adult Life - excellent, positive but practical. Fab team
- All the info
- Discussion with Preparing for Adult Life about forthcoming changes to income
- All the info available. Stands were excellent. All the workshops
- Keynote speaker's talk and workshop on Preparing for Adult life
- The stands with information about groups and short breaks
- the ASD pathway workshop and speed dating
- The info from stands
- All the stalls and info provided
- Speed dating , education advice
- The variation of stands and the info available
- Found out more about EHCP and what help is out there, and that you are not on your own. It was really lovely to meet new people.

- Stalls
- The range of info available to parents carers and professionals alike
- Everything!
- All of it
- Networking, seeing what's out there for the future
- Lot of great information
- Getting info about all the different services available
- Everything. The level of knowledge - range of advice was fantastic
- Talking to professionals
- EVERYTHING! Stands, workshops, networking
- Speaking with professional at SEN Support workshop. SEND Partnership. CAMHS workshops
- All the stands, the leaflets and people to talk to.
- Lots of information from various organisations all in one place
- Keynote speaker's presentation
- Lots of info available and all stand holders very patient and passionate about the services that they provide
- Talks very clear and informative. Expectations for SEN support was excellent
- All useful
- Networking
- Information and advice
- Very informative throughout
- Info I had received was wrong on transport so now I know what to do. Also love the range of information on offer
- Info on ASD pathway
- New info and seeing other services that I can access
- Morning workshop about transition. Stands and speed dating
- Leaflets and information. Talk from social care
- So much information

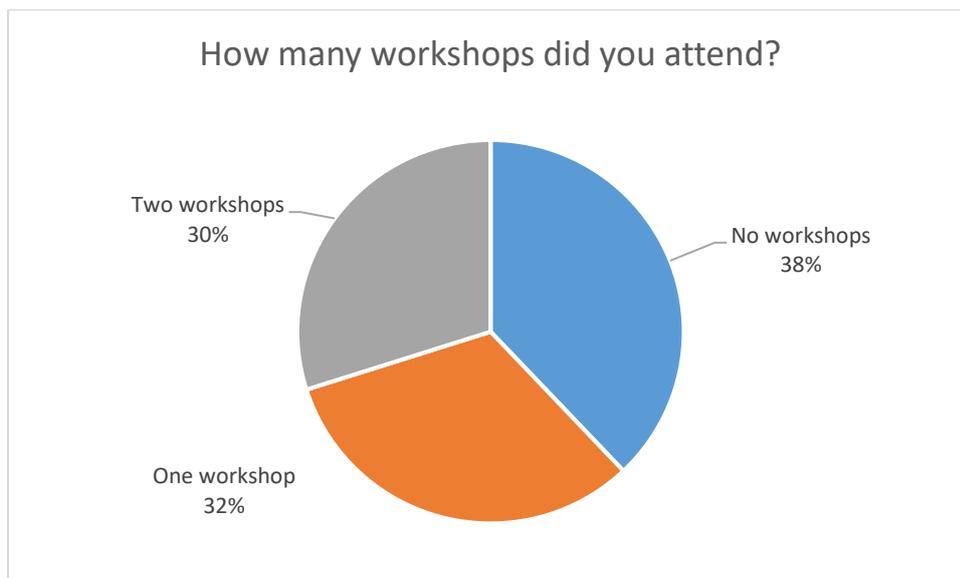
What could have been better?

- More for age 21+
- More time for Q&A w keynote speaker
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- Keynote speaker was excellent but needed more time for questions. For such an emotive subject, it was upsetting that some people were unable to ask a question. The answers would have been refreshing for all to hear.
- Food - catering forgot to make me a sandwich, even after ordering one specially
- Queues to register, don't split by surname as some queues were longer than others
- Practical workshops - managing challenging behaviour
- Workshop on SALT would have been useful
- More time for Q&A w keynote speaker
- A longer day

- My young person is 25 this year so more relevant stands / workshops would be great. More on employment opportunities, supported living and post 25 needed
- A jargon buster given at reception about with the programme
- Better access for people who do not have transport
- More college stands
- Nothing - fantastic conference
- Legal advice stand for when things go wrong
- Keynote speaker needed longer to answer questions. Too many figures and information in her presentation.
- More time for Q&A w keynote speaker
- Quiet area and more seating to have lunch and coffee. This is our annual outing where parents can off-load and compare and share. Somewhere nice to do it would be lovely.
- I think that the conference was good. Our son is fairly settled at the moment so needed limited assistance compared to previous years
- Longer workshops
- Not much
- All very good
- More chairs
- My first year!
- 2 hour break between workshops is very long
- Nearer the West
- More spaces for speed dating
- Job opportunities for older age group 18 - 25
- More time for Q&A w keynote speaker
- More about moving to high school
- Longer day, do more workshops
- More for post 18
- Difficult to get food - no plates or napkins - but food was great
- More time for Q&A w keynote speaker
- Not having lunch in the foyer - too cramped
- It is quite cramped and loud so maybe more spread out
- Legal advice clinic around tribunals, discrimination
- Bit more for younger children
- More time for Q&A with Sara. Parents needed time to ask their questions.
- More spaces for speed dating
- Slightly more room around the stands
- More commissioners there
- Inviting adopters and foster carers. More Q&A with keynote speaker. More speed dating appointments
- Having access to EHCP draft editing to be robust here and now, not later workshops
- Joint with Suffolk providers so they can showcase their organisations. We live in Lowestoft so some organisations not relevant to us. No plain food for those with dietary needs

- More time for Q&A with keynote speaker
- OT stand - parents who have been referred for OT struggle to access services as having an OT assessment seems to be a prerequisite for all other services being able to help.
- More room in workshops
- More area around the stands
- Shorter lunch break - a third workshop / Q&A session. Too much time.

How many workshops did you attend?



Your comments about the workshops attended.

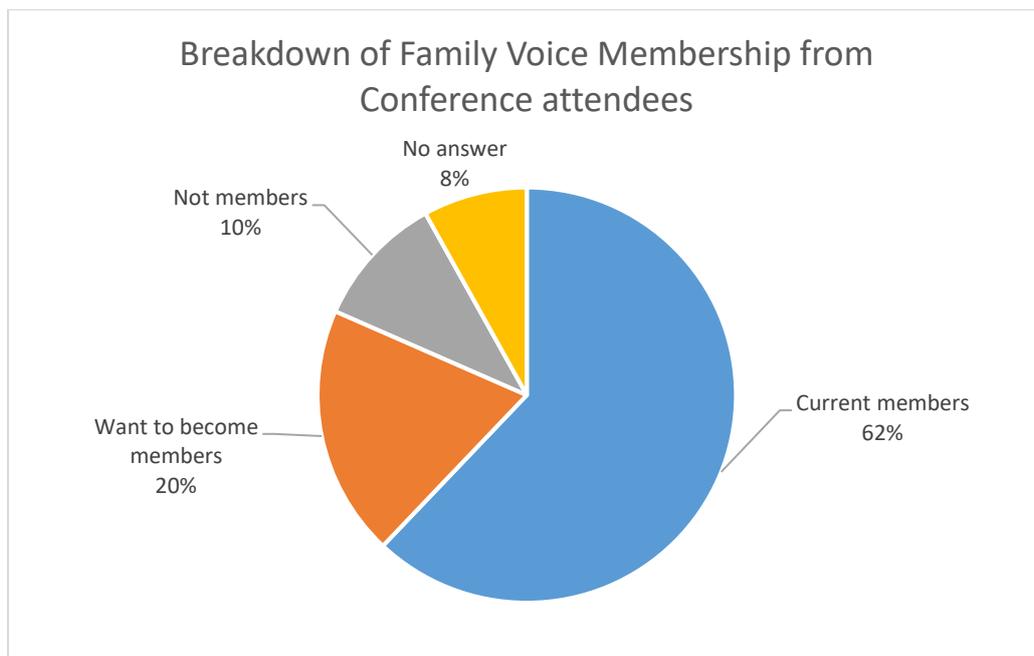
- ASD - good to know what you should have.
- ASD - info on procedures & Young carers - less helpful. I ended up talking to one worker after about engaging YP online and leaflets
- ASD - interesting to hear about the "improvements" in the pathway but wonder how realistic they are. It is always interesting to hear views of other parents and have the chance to give feedback to the organisations on how to improve.
- ASD - only attended one workshop as others not relevant, good to understand the process and requirements, also useful to understand the pressures
- ASD - very informative
- ASD - very interesting and relevant. Unfortunately too many people making it personal
- CAMHS - not directly relevant for my family but v interesting to hear about the set-up of CAMHS service
- EHCP - more questions taken
- EHCP - more visuals / leaflets, more user friendly
- EHCP - useful reference to the law. Would be good if copies of the slides were provided or available online
- EHCP - v good

- Just one Norfolk
- Just One Norfolk - exciting new services, potentially useful
- Just one Norfolk - finding out a lot more about the website
- Just One Norfolk - helpful mix of presentation, visuals and question time
- Just one Norfolk - new service for young carers
- Preparing for adult life - brilliant
- Preparing for Adult life - excellent
- Preparing for adult life - presenter was great. Very informative and very helpful
- Preparing for Adult Life - very useful and informative, Annual reviews - delivery was difficult to follow. Much appreciated that both were not side-tracked by individual questions. Would like workshops about older children
- SEN support - fantastic speakers

Any other comments

All of the parent carers would recommend the conference to a friend and 95% said that they would like to come again.

Parent carers do not need to be members of Family Voice to attend the conference but many chose to sign up afterwards



- Thank you
- Will slides be available to us via email?
- A really, really useful day. Thanks very much for all your hard work.
- Thank you so much for arranging this event. It is the ONLY chance as a parent where I get to find out about current support and information to help our family.
- Thank you so much. Thank you for the childcare. If there was no childcare then I wouldn't be able to come.
- Excellent day. Well done everyone!

- Lunch is excellent
- Keep going. You are fabulous.
- Excellent conference
- Fantastic. Thanks for putting it all together. Needed more time
- Thank you for helping us to not feel so isolated
- What a fab day. Keep up the good work
- Keynote speaker could have had more time for taking questions, as she does not meet the public often. FV - well done to all the organisers
- Well done and thank you
- At times it was difficult to hear the speakers (keynote and workshops) due to noise from young children
- Always an excellent event in where I come away with some useful information
- Always a great event. Well organised and lot of useful information all under one roof, not to mention a scrummy lunch and yummy pastries. Many thanks for your hard work.
- Thank you
- So refreshing to see how much more support / help / advice / services are out there now for our children / young adults with SEND than there was when my now 22 year old was young. Well done
- Well done and thank you
- I found the speech keynote speaker was good but I found that some people were rude, butting in and being rude about Family Voice staff. Not a very nice experience and it was very unneeded
- Sandwiches were awesome! Love sandwiches.
- Thank you for a lovely day and all the help was great
- Brilliant event - would love to attend next year
- Special dietary foods were rubbish. Everyone else had a buffet choice, I got a jacket potato with beans and not option except fruit for a dessert, which I had to join a queue for. Also no seating to sit and eat a jacket in a civilised way. Could have provided wraps.
- A HUGE thank you for an AMAZING EVENT!
- Thank you all! Excellent idea, excellent venue, excellent food
- Thank you. Very helpful. I hope we all get what our children need and deserve
- Very good venue. Food very good
- Food! This is a conference that deals with children with ASD. Therefore, a lot of parent are also like this. The food was mixed, unlabelled and the sandwiches were mixed (cheese and tomato). The food stands freaked me out and I couldn't eat anything
- Best ever
- Brilliant day

General Comments about Services

Parent carers also have the opportunity to fill in our Red and Green Cards. These ask parents two questions, "Thinking about your child or young person with SEND,"

- On the Red Card, "What is NOT working well right now?" – 39 responses received
- On the Green Card, "What is working well right now?", and 25 responses received

Not working well – Red Cards

Education

- Implementing the level of support that is written into EHCP
- EHCP – No annual review called. Unable to get provision quantified. Unable to get sensory integration or SALT in EHCP
- The EHCP process! Applying for year 3 place in special school or appropriate mainstream year 2.
- EHCP placement teams are not working well for us
- Applying for an EHCP where the school has not completed their part
- Needs more help in high school
- Finding good options for secondary transition between mainstream and special school
- My son is in a complex needs school, has a badly written EHCP and a personal budget. Yet I have never met anyone from the local authority, including his EHCP co-ordinator in person!
- The LA talk about early SEN support to avoid high-needs specialist placements. To achieve this, the LA needs to provide Independent SENCOs that parents can talk to, to check the support (or lack of) is appropriate. It is hard to challenge schools as a parent. Our SENCO came up with lots of reasons we could not apply for an EHCP, even after 3 years of problems and reasons that the school could not implement more support. I cannot help thinking that earlier external support might have helped our child gain support that is more inclusive. The SEN system in schools relies too much on one individual – which is great if that person is good, but not otherwise.
- My child's school provides enough care for his needs so his EHCP was refused, but what happens when he goes to high school???
- Lack of communication from LA about my child's placement
- Teachers and TAs need SEND training!! Just having one SENCO in a high school is no good. I have fought for help for my son (who has Asperger's, ADD and OCD) since he was 2 years old. He is now 16 and has been a school refuser and still we have no help! Now he is 16 he has to fill in his own EHCP and he will not! He is in total denial and refuses help!
- The gap for students on SEN register that don't get the TA support in class compared to students with an EHCP
- Ration of adults to children with complex needs means that the children are not safe
- EHCP co-ordinator giving incorrect information during diagnosis process and was not replying to emails. My child is only able to access part-time school for one year at aged 8 and we can't get an appropriate school place
- Getting the mainstream school to follow the basics in my son's EHCP
- Communication within Children's Services is not working for us. Everything is a battle and a constant time-consuming thing. I have spent the best part of a week trying to get hold of our EHCP co-ordinator. Despite leaving messages, these have not been returned or replied to.

Health

- Sensory therapy needed asap – it's oversubscribed
- Not receiving the services that my child needs. Undiagnosed ASD. He has other problems including lots of headaches and diarrhoea. It is difficult to get a doctor's appointment and some services require more evidence than I have. As he is high functioning, he is doing well academically but misses a lot of school do to his health.
- OT is a struggle to get. Waiting times are far too long
- Speech and Language needs to be greatly improved
- ASD diagnosis delay and poor communication
- Girls with ASD – diagnosis, services and recognition is so much slower or not at all!
- Insufficient funding for sufficient SENSI therapy. It works! We receive the maximum but more input now could mean less needed later in life.
- It takes so long to get a report following an assessment
- Lack of access to OT / SALT, lack of funding for OT / SALT. Diagnosis pathway via NHS and likely diagnostic outcome

Social Care

- Short Breaks provision in the West is an issue
- Closing residential respite
- Closure of overnight respite facilities and "downgrading" of children's needs so that they no longer qualify for respite or Short Break support.
- Anxious of possible budget cuts to personal budget funding may have potential impact on funding my son's day services and therefore my ability to work and pay bills, which leads to uncertainty over whether we will need to move house etc. Now exacerbated by forthcoming changes to minimum income guarantee
- Getting Adult Social Services on board

Lack of Support

- Lack of information for those whose child is not biologically theirs. I have a special guardianship order of my child with SEN and it's very difficult to find out anything
- Lack of understanding and support for impact of trauma on mental health
- I found getting any support for my child very tricky. I also found that the lack of support has had a negative effect on her mental health. It has also impacted the whole family
- Following the keynote speech: We spend 2 years as "crisis but not crisis enough" according to services. As a result, our wonderful son did not get the specialist support he needed early on. It was too late when the crisis team came. As parents, we knew that NCC had no idea how to help our son and us and had no provisions in place. My son is now in a residential placement over 100 miles away. It was the hardest decision. Our son is thriving now and we see him every week. We need more early help but the services are not taking children on – services are too busy – staff shortages - families are suffering – children are being let down.
- Family support for family with child with high functioning ASD. There's lots of emphasis on school support but once you are in a home environment and suffering horrible behavioural challenges, there is no support available
- Lack of knowing where to go with a child in year 10. What kind of support is there? What is the future for a child with invisible mental health issues

General

- Downgrading children's needs so that services do not need to be provided
- Activities based in Norwich not West Norfolk
- Need a list of all the jargon!!

Working Well – Green Cards

Education

- My child is getting certain support from his new specialist provision
- High school is working well at the moment
- Support from school is fantastic. Good 1:1 communication and open to input from parents
- Some high schools are more understanding of mental health than others and providing cooling off rooms for the young people to go to
- My son's mainstream school is working well. He is taking his GCSE's this summer. When I look back at his last year of primary school, I cannot believe how far he has come and how he has coped so well with high school. He has had a very few incidents and has flourished and matured beyond my hopes. This proves that with the right school and the right support, children with SEND can join in mainstream education.
- In the right school (finally)
- Good TA with 1:1 at school and good SENCO
- He has settled well in his new school and made friends that are older than he is. He really enjoys maths, English and drama lessons
- The Tribunal process worked well for us!
- My child's special school is fab! 😊
- My son goes willingly to school
- My child's special school has been amazing. Transport has been good and offered flexibility and delayed a change

Health

- Good SENSI therapy
- Sensory therapy
- Keyworker scheme
- Play therapists at the A&E department of the NNUH were really helpful
- We are currently under Starfish and have found their service good for assessments. Unfortunately, due to lack of personnel, they have been unable to meet our son in school. The epileptic team at the hospital has seen our son and they have been excellent.

Social Care

- Good social worker
- Adoption services have been great
- Short Breaks funding approved quickly – no fuss, no battle and very helpful
- Marshfields Respite provision is great but cannot cope with the number of children needing its services

General

- Attending Family Voice events, meeting other families and sharing SEND information via support groups
- Family Voice conference
- My son has settled in brilliantly at a care farm where he goes to “work” four days a week. He loves it there and they love having him. I can see him staying more (working more) indefinitely, as long as the funding stays in place
- This conference has been AMAZING. So much wonderful advice and so many dedicated professionals and volunteers

Bernadette Pallister,
Administration Manager, Family Voice Norfolk
October 2019