



Family Voice Norfolk Conference

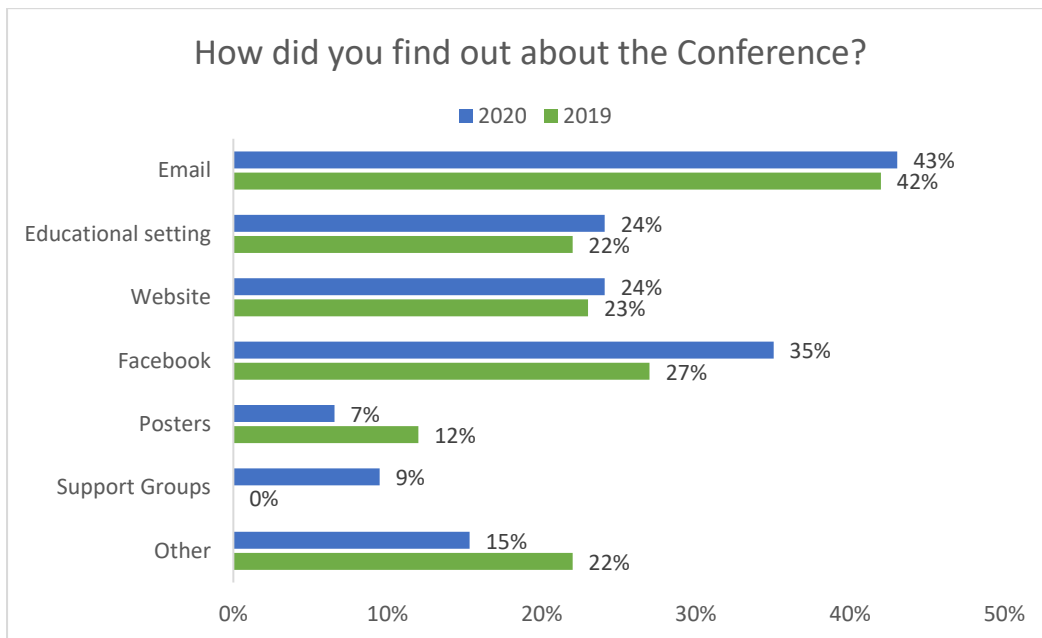
Saturday 14th March 2020 at the John Innes Centre

Appendix: Data and Feedback

The tenth Family Voice Conference was attended by 252 parent carers and 144 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 155 feedback forms from parent carers and a further 49 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.

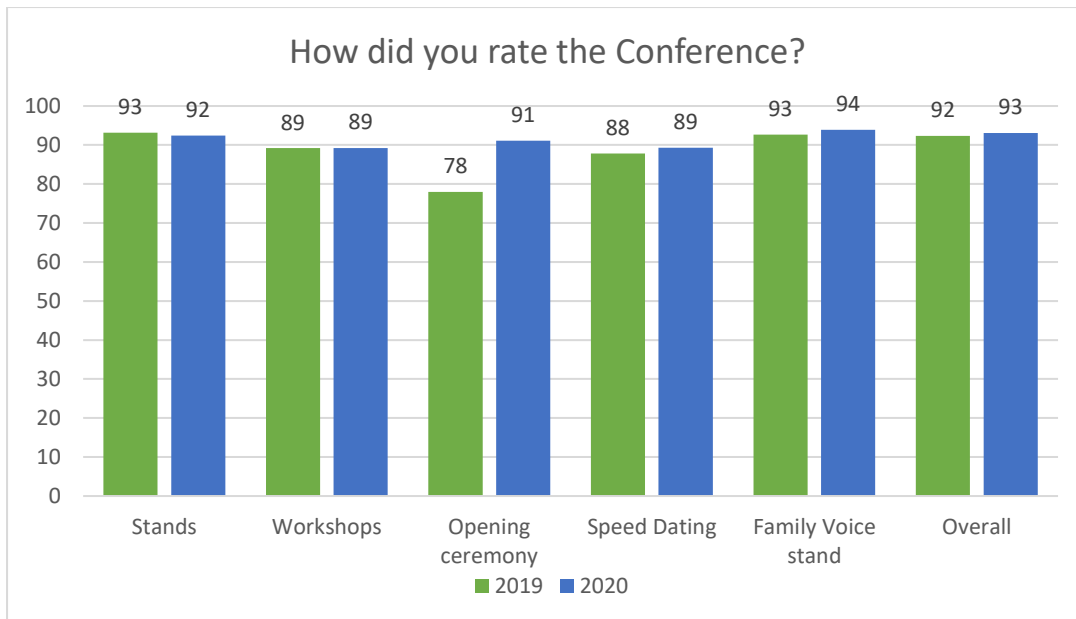
About the Conference



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?

- Lot of signposting and information
- All people under one roof
- Lots of different services that I didn't know about that I am now able to reach out to.
- There is always lots of information available at this event
- Information on various organisations
- Great diversity of information
- Interesting information
- Friendly environment with lots of helpful ideas and information
- All the different stands and advice
- All of it
- Always useful to see what is available
- Great information
- Good selection of stands and workshops, which had plenty of information for parents
- All support services in one place
- I liked all of it
- All the information and stalls
- Finding out about new services and support
- Information and workshops
- Lots of useful information around different areas of need
- So much help and information in one place
- Lots of information about a variety of topics and issues
- All info was very interesting but from 18+ was very good

- Lots of information available
- Finding information on all the activities in the area
- Finding out information in a relaxed environment and face-to-face
- The variety of information
- Everything – I have managed to get help and answer a lot of un-answered questions
- Information over load. Change to mix with similar people/ issues.
- Information
- The amount of information and advice available
- Very informative, lots of ideas given to try for ourselves.
- Amazing
- ASD helping hands recommended it last year and we came to FVC 2019. It revolutionised our family life. We learnt SO much that we had no idea about. We came again this year and cried at the D4Dances. We have again been blown away by the amount of information here and the displays. I attended a speed dating session with a health professional, who was lovely and I hope that I gave him some tips about SEN parents, NDS waiting times. He was very approachable.
- Being able to bring my YP so that she could also understand how her SEN should be supported at school.
- Thank you for putting together such a useful and informative event. A lot of helpful people with lots of leaflets to take home and read.
- All of it
- Everything
- That carers matters
- Everything. All very helpful
- Everything
- Speaking to organisations on the stands, the SEN in schools workshop and being inspired by the ethos of the conference (to carry on fighting for my child's needs to be met)
- Lego kept my daughter happy while I talked to the man about wills and trusts
- Hearing other parents' struggles and not feeling alone. Being able to have my say!
- The whole day was, as usual, very good. Networking with other parents and sharing "issues" and successes is always good.
- Meeting other parent carers and the PDA workshop
- We enjoyed the event and meeting and talking with all the people
- Connection
- Chance to catch up and encourage others. The Family Voice chair did well with her introduction from a parents' perspective.
- Meeting lots of people
- Stalls, networking, meeting parents.
- Networking, shared experiences, info.
- Meeting other parents. Speaking to professionals
- Love the opening speech and dance displays – awesome!
- The dancers – they really gave me hope for the future for my daughter. Much better than the speeches from last year.

- The dance workshop and preparing for adult life
- Speed dating
- Speed dating and cake
- Speed dating and Q&A
- ASD helping hands for the speed dating, SEND workshop and information stands
- Speed dating
- Speed dating and Q&A
- Workshops and speed dating. Great advice from PDA. Time to speak to lots of different people who understand
- The opportunity to speak directly with people such as Michael Bateman. So many people are accessible and having face-to-face conversations is invaluable
- I got so much information and help about ASD from Helping Hands. From help about short breaks to helping us with an EHCP. Also spoke with young carers about my other child getting a break
- Speed dating, talking to people with actual power to help you individual case
- Very useful specific workshops. Speed dating – brilliant.
- The volume of stands. The workshops and speed-dating supporting children at SEN support in mainstream schools.
- Speed dating. Steph Askew workshop.
- Speed dating, but all extremely helpful
- Q&A. Speed date
- Speed date. Q&A
- Information about mental health and transitions from child to adult
- All the stalls
- Stalls
- Interesting, informative, relevant, positive stands. Real help, support and opportunities
- Stand and information made available
- Huge range of exhibitors providing support for families and children
- Lots of useful information and a variety of stand. Helpful people
- Information from Norfolk SEND partnership
- Talking to those on stands who have good knowledge of SEN Children
- Variety of stands and information
- The information stands for gaining information about services
- Talking to people of the stands and picking up leaflets for extra help
- Talking about transport with the TITAN team
- Stands for short breaks, legal requirements and the Garage
- The amount of professionals and information stands
- Stands
- All different services available
- All the stands were very helpful and gave very good advice and support
- Gathering information around development and SEN/EHCP
- Everything – great day, learnt so much, great stalls.
- Great stands and speakers

- I found that the national Autistic Society now has an office in Norwich, very helpful.
- Speaking to stall holders
- A chance to chat to the experts
- Talking to stands about support for physio / SEN
- The wide variety of stand and specialists, and the opportunity to talk with them
- Liaising with different groups
- Access to providers
- Getting to speak with professionals directly to get information
- Networking – finding out and keeping up to date
- Meeting people and sharing information
- Opportunity to talk to people who have experience of parenting a child with ASD and where to go for help and support
- Lots of contact with professionals and also with others in similar scenarios as me, who understand
- Being able to talk to people from various organisations
- Speaking to people with specific issues I had regarding my son
- Being able to meet people face-to-face and having several agencies all together
- Being able to talk to people face to face
- Stands so that I can meet people directly
- Ability to speak with difference providers
- Meeting people from difference organisations under one roof
- Getting my questions answered
- Being able to meet people face to face about areas we need information on
- The workshops on SEN support and PDA
- Had a successful day about making a will and talking to the police
- Workshops
- Stalls and workshops
- The Q&A session workshop
- The workshop talks
- Workshop on PDA and talking to Norfolk SEN Network about EHCP advice
- SALT, meeting new people
- Information around transition to adult life
- PDA talk
- PDA workshop
- Workshop on PDA
- Kind and helpful people, PfAL workshop, variety of information stands and lots of very useful information
- SEND remain in mainstream, PfAL
- The workshops and information leaflets
- Having more workshops throughout the day
- SEND in mainstream talk in the morning gave helpful and useful information
- Workshops and stands
- PDA talk

- The Q&A session in the auditorium
- Mainstream school talk was really interesting and the information received we can now share with the school
- PDA session and support children at SEN support
- Info from Q&A with key people and speed dating was so good. I enjoyed the stands too
- Speech and language therapy session
- Short break info. Workshops on PDA and supporting SEN in mainstream schools
- Q&A session, interesting hearing views of parents in similar situations
- Q&A session. Nice to hear views from parents in the same position
- Help and advice re ECHP reviews. Help and support available.
- The PDA workshop
- Workshops on supporting SEND children in mainstream schools
- Attending a workshop and finding out about services
- The workshops
- Workshop and stands very informative and helpful
- The workshops were very helpful and informative. I liked being able to visit and talk with the exhibitors.
- Workshop were excellent.
- Information about SALT.
- I enjoyed the dance workshop very much and the 'preparing for adult life' workshop

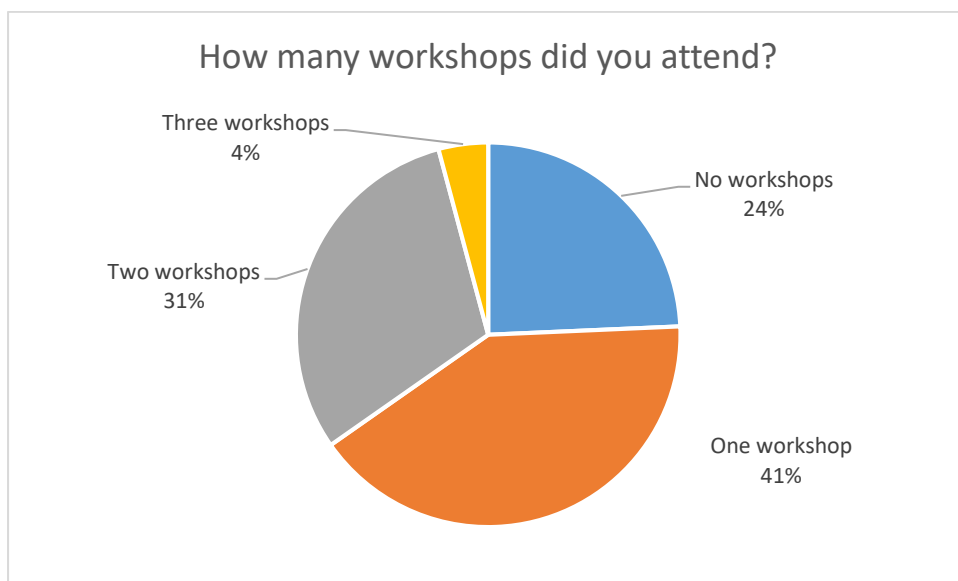
What could have been better?

- More children's activities
- Nothing – except maybe more than just Lego for the children to play with, such as drawing, games, activities
- All day lunch as when attending workshops you run out of time
- All day lunch! Not enough time to eat :)
- Drinks available with the food (which was excellent)
- Food. It ran out by the time we were able to get to lunch – 1pm
- Food – it ran out when we went (1pm)
- Food was nowhere near as good this year. It was already stale and ran out early
- Longer. Food
- Lunch – limited choice
- Lunch – food had run out by the time I went round.
- Lunch! It had finished when we went in there (much earlier than it was supposed to) so we had hungry and upset children
- More cake
- More food
- More food at lunchtime!
- Sandwiches were dry
- Should have been drinks available closer to the lunch area
- Some more cake

- The lunch seemed to disappear quite quickly!!
- They took away the pasties too quickly so I missed out. Two workshops on at the same time that I wanted to attend.
- Just didn't get info on parking and worried about where to park
- Maybe set up a quiet space.
- No coronavirus!!
- Seemed a bit down on numbers and organisations – not your fault!
- Too hot?
- Very hot inside
- We missed the keynote speech due to not having transport, and timed it wrong
- Would have liked to have been picked by Katy to dance on stage
- A bit more time! I wanted to attend 3 workshops AND speak with lots of stands and it was all very full on. Many stands didn't turn up due to corona virus. Ran out of appointments to see the speed daters
- Longer day. Repetition of most popular workshops as the two most relevant to us were on same block.
- Longer for the PDA workshop
- Longer needed for the PDA workshop
- Longer time on the workshops
- More time to speak with individual services
- More speed dating appointments
- More speed dating sessions please
- More speed dating slots. I got there at 9:20am and most slots were gone already. Most stands packed up about 30 minutes earlier so we missed a lot of stands
- More time for speed dating
- Any information on help for siblings of disabled person
- Disappointed that some stands did not come
- Each stand could have been numbered as per book layout, making it easier to find what you're looking for
- Information on EHCP
- More autism focused advice
- More for ages 18 – 25
- More stands with local activities for children with SEND
- Nothing for dyslexic children
- Representation from Newberry / NDS
- Some info on sensory therapies
- Stalls that offer support specific for parents
- Wanted to see Nansa – sadly not in attendance
- Air conditioning! Please don't put on talk concurrently as I don't want to choose between them
- Bigger rooms for workshops
- Couldn't attend the PEASS workshop as too busy. Possibly, switch to the auditorium?
- Difficult to fit everything in because there were 3 workshops

- Filling in feedback forms after workshop. Don't mind at the end of the day
- I really wanted to get into the SEN Support workshop but it was packed. Need a bigger room. Same happened last year.
- Larger rooms/more seating for the workshops that are likely to be overcrowded
- Maybe holding two workshops at a time so don't have to chose between (or repeat the big ones ie EHCP)
- More seating
- More space in the workshops
- More time at the Q&A workshops
- More time in Q&A
- More time needed for PDA workshop
- More workshops
- More workshops relevant for the 18+ age group (improvement on previous years)
- Not enough room in the SEN support workshop
- Please could all workshop leaders head up ground rules around participant behaviour and confidentiality?
- Some workshops were very busy and people coming in very late and leaving doors open was quite disturbing
- The PEASS talk was rammed full and a door person would have been useful to prevent overcrowding.
- When workshops are full, need to try and stop people opening door as noise is off putting.
- Workshop on ASD social communication
- Workshops on at the same time that I would like to have attended
- Workshops need to be more spread-out
- Workshop on ASD social communication

How many workshops did you attend?



Your comments about the workshops attended.

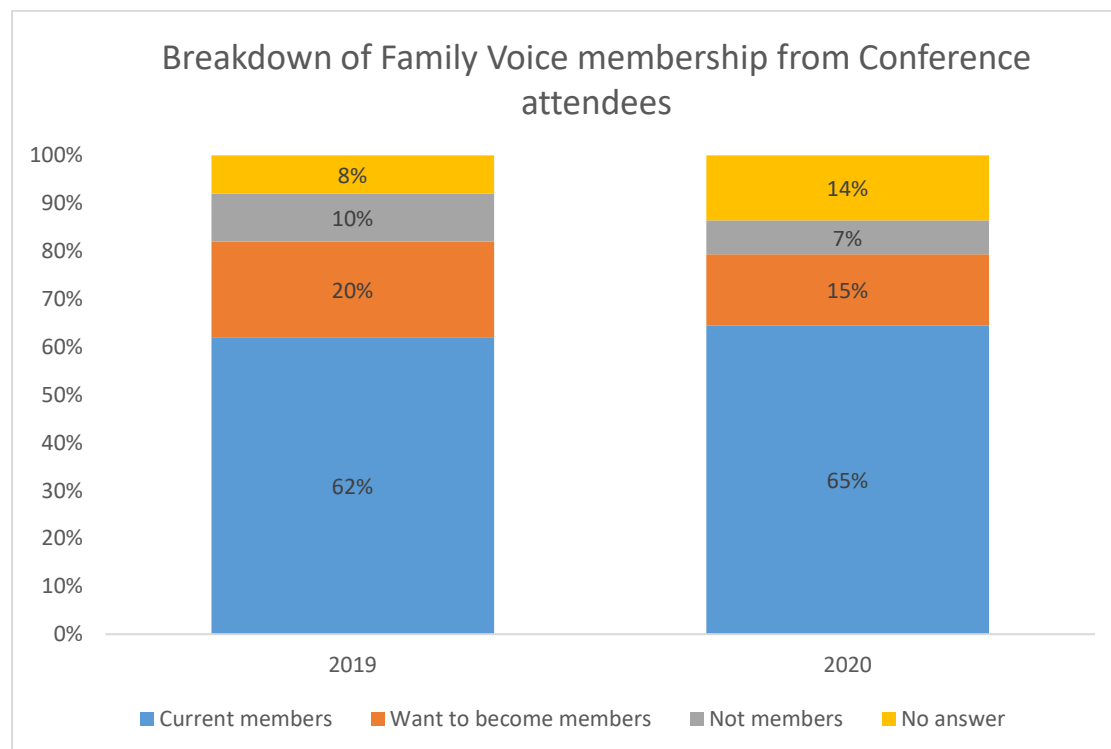
- DPSS – useful info for myself, plus also for friends who could not attend
- EHCP – Brilliant, Amy clearly knew her stuff, plenty of time for questions
- EHCP – informative and good to have question time
- EHCP – great, I take so much away
- EHCP – finding out the full legal process and what should be done.
- Hospital Encounters – not quite as advertised
- PDA – needed more space, great for similar minded people
- PDA – some clarification of PDA, we need strategies. Thanks for signposting to further info.
- PDA – useful for background information and demonstrating exactly the role of Family Voice
- PDA – very crowded, needed more space, more information about condition
- PDA – great to hear other parents/ careers experience and how by working together changes can be made.
- PDA – lots of people trying to get their stories across. More reference to PDA society would have benefited some.
- PFAL – was useful in the fact of my life opportunities.
- PfAL – good info provided but less relevant for me as my YP is over 18
- PfAL – sounds good in theory, hope it works in practice
- PfAL – very useful. EHCP in year 9 to start referral and planning
- PFAL – If I hadn't attended I wouldn't have had a clue about referral process, seems to be based around complex needs schools (not all slides suitable for visually impaired).
- Q&A – great to have such a wide, honest panel
- Q&A – parents realise the danger of peer isolation by having to go to complex needs school, big stat where only 3% of special school pupils end up in employment
- Q&A – found the whole experience very useful
- Q&A – I liked the different agencies involved.
- SALT – informative
- SALT – very informing
- SALT – very useful, not sure what I would change.
- SEN Support – informative
- SEN Support – felt like it was written for teachers and not parents
- SEN Support – it was really helpful to be able to talk to the speakers about your individual circumstances.
- SEN Support – the existence of the PEASS document will take back to school to encourage them to implement helpful strategies and be more accountable.
- SEN Support – useful information
- SEN Support – very helpful as we are at the beginning with thinking about an EHCP for our son. It has really helped me gain a better understanding of the process
- SEN Support – Very informative and detailed regarding schools SEN provisions.

- SEN Support in mainstream schools – Fantastic. I now have knowledge on what my son’s school should do.
- SEN Support – Presentation style. Range of information. More time for questions would improve.
- SEN Support – son is now attending high school so good to know what I should expect
- SEN Support – Lots of useful information about what support our child can expect at school. Wasn’t enough time for a Q&A
- SEN Supports – great, I take so much away
- Total ensemble – Dance was useful in the fact I have an interest in it.
- Will Maker – Not bad could have been a bit more with relevant examples
- Will maker – tried to get in but I was very late due to talking to stand holders
- Will maker – useful info
- Will Maker – useful information albeit a whistle stop tour
- Will maker – very good, informative and useful to those attending and answered some questions that I have (although I already have a will and trust for my YP)
- Will maker – very useful
- Will maker – very interesting, easy to understand.

Any other comments

All of the parent carers would recommend the conference to a friend and 99% 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! :)
- Attending the workshop on building schools and how our children are in limbo until then
- Opening speech was really good – fantastic performances
- Love this event – really look forward to it every year.
- Keep up the good work :)
- I am very pleased to have your help and this event helps me a lot. Thank you.
- The children always really enjoy and look forward to this event. The family atmosphere and opportunity to relax is brilliant. Thank you!
- Thank you
- Thank you from the bottom of my heart for all your wonderful work. You make such a difference to so many lives.
- Wonderful event – very helpful. Thank you.
- Needs chocolate cake
- Thank you
- Fantastic as usual
- Excellent, informative and fantastic to meet other parents too
- Really enjoyed the performances during the opening ceremony – a wonderful thing to include!
- Thank you
- Thank you. All the best!
- Having the lunch longer and having more workshops was really helpful
- FV staff are always welcoming, friendly and enthusiastic and help make the atmosphere warm and positive. Well done to you all. Keep up the good work, which is very much appreciated. See you next year!
- Excellent day once again. Many thanks to all involved in the very organised planning and arranging of the event. PS I LOVED the dance groups – they were amazing!!
- Thank you for a great day. I would highly recommend to others. What you do is invaluable.
- Thank you again for such a well organised, useful and hugely informative day :)
- Thank you so much for going ahead with the conference this year. You could tell that a lot of hard work had been put in. It is something that I attend annually and each year I take something new from it!
- Thank you for a brilliant and informative event
- Yeast and dairy-free lunch was good. Carrot cake was the best. All other lunches gone by 12:45pm
- I thought that this year's conference opening ceremony was lovely. The performers were a credit to the groups. Every year that I attend, I always come away with a nugget of information. I wish that I could contribute more to Family Voice but I am restricted for time at the moment.
- Really good, friendly, helpful conference
- Thank you for organising this each year. As a SEN parent where you often feel neglected, it's lovely to have an organisation that supports us. Thank you.

- Well done with going ahead with the event
- We have been coming for several years and the conference has been a great benefit to our family
- It was useful to bring my son with me as he has attachment issues and to be able to come and go as needed
- Thank you so much!
- My favourite is the food!
- Brilliant informative day. So glad that I came along and a big THANK YOU!
- Fantastic event – so valuable – and seems to be the only place that you get to actually find out information that you need. Also very inspiring (loved the performances as well. They were really moving and fantastic pieces of work).
- Very well organised. Very useful information
- Well done, fantastic event.
- Next year: school transport. Attendance policies. I'd like to be involved in either
- Really appreciate all your planning but still had to wait ages for my lunch! (re. allergy) Drama and dance performances were amazing, good to children up there. Thank you for organising Lego club, workshop and suitable keynote speech for them to attend.
- A little difficult to hear in the workshops
- The dance groups were exceptional – very moving
- Fantastic. Really focused on family parent voice and able to speak with many professionals. First time at the conference and it was such a wonderful positive place. I do not feel alone now.
- Thank you. I couldn't find the EPSS stand though
- Very good event. Very helpful and informative. Wish I had found it years ago. More help and support needed for 16 years +
- Portage team was really friendly, polite and provided helpful advice
- Thought that it was well presented and organised. A great opening ceremony and introduction to the event.
- Thank you!
- Amazing venue and fab catering. Thank you.
- Thank you for putting this on
- Thank you!
- As always well-presented and informative
- It's great that this happens. Shame that there were less stalls this time but people were very friendly and helpful. Very unfortunate about the lunch through. I just wish I could attend more of it but caring responsibilities make that tricky.
- It was more exciting/ interesting than I thought.

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? – 25 responses received

NOT WORKING WELL – RED CARDS

1. Dentist – Most practices decline applications to see children with SEN needs or are not equipped to, or worry about their insurance! The only way a child with SEN can get dental care is through referral and that is only if there is a problem – so they can't access the same basic dental care as a child without SEN needs. Discrimination!
2. The lack of support and understanding from the school.
3. Lack of resources i.e. money for SEN provision in mainstream. Lack of understanding of the causes of behaviour in mainstream.
4. Communication between different services. Schools not implementing things to meet child's needs.
5. School not supporting wellbeing needs enough.
6. SENCO keeps changing but we're not told. Not had review for 18 months of child's care plan. Feel lost!
7. School, staff and management.
8. Hobbies and activities outside school – hard to find something for him to engage with or that is available.
9. Son diagnosed with ASD. Diagnosis given to mum and dad only, son (14) not included. On waiting list for 'puffin' group. Not sure how long waiting list is. School SENCO is very good but nearly 3 months later we haven't got a 'pupil passport' at school.
10. Everything is such a long progress. So frustrating and sometimes feel you get no support at all.
11. Communication from LA. Waiting time for educational psychologist assessment 16 months! Not enough specialist provision. EHCP not enough to get support.
12. My son (14, ASD, mainstream high school) is failing academically even though he is super bright, and, as a parent, I'm struggling to find how I can get his needs met. It's daunting, frustrating, painful watching him fail and knowing that with good support he would be soaring. School isn't doing what they should and I have no power to activate anything to 'move' them (probably should have said encourage instead!) Why is it they don't just support in the right way as a matter of course?
13. Getting the right support. OT has said sensory circuits. School has said no money. So he is getting over anxious/excited (diet coke bottle), bubbling over at home. Creating very bad day at home.
14. Delays in EHCP system, lack of educational psychologists. Lack of available medical needs support.
15. The SENCO!!
16. Lack of provision for their needs at school. Time on waiting lists as without a diagnosis my child's school won't help them.
17. We put support in place then it seemed to work for a while then it just stops.

18. SENCO at school refusing to put on SEN register despite son being accepted by NDS for diagnosis a year ago – 3 year wait for diagnosis.
19. Level of support has been reduced in school and she thinks she needs more support than she is currently getting.
20. Inflexibility in school.
21. Inclusion in community. Speech and language therapy access.
22. We need a service for young people 18-35 years like Family Voice to help us help our young people. Some of them need extra help for life.
23. No help or support for 18 years +
24. Acknowledgment from school that my son has SEND (ADHD, Aspersers /ASD)
25. Norfolk 'therapeutic' provision is NOT therapeutic. Hamstrung by usual delays and inadequate staffing/ resourcing issues.
26. The length of time waiting to have ANY kind of health assessment. Having to wait 8 years to get help is unacceptable and ultimately damaging to child's development.
27. It has taken such a long time to receive an educational psychologist report/ assessment and now we are told that we have to wait 18 months to see an NHS consultant. In the meantime, we are not convinced that my daughter (9yrs) is receiving adequate schooling. She is ASD and has dyslexia and anxiety. Refuses to go into the classroom several times a week. It has been extremely difficult to meet with the school's SENCO. Although it has now taken place we have not received any follow up correspondence as promise. We feel very let down by the process.
28. We had a diagnosis of ASD for our 14-year-old son in December 2019. We have to work out for ourselves what to do next. He hasn't been given the opportunity to talk with professionals who made that decision about this diagnosis and how he can move forward. No information on where he is in the ASD spectrum.
29. Knowing where to get the support when you have more than one child with SEND but do not fit into services boxes.
30. Getting a special need school for my son for year 6 and going to high school.

WORKING WELL – GREEN CARDS

1. The Family Voice conference is a fantastic place to meet and see some of the amazing resources and information that are offered to a parent with children with SEN. Thank you.
2. Attending the FV conference last year literally changed our family's lives. So much advice and so many services we never knew existed. We attended this year with our ASD/ADHD sons and again have gained so much from the day and it was perfectly set out. THANK YOU ALL SO MUCH FOR ALL YOU DO!
3. Well done! Such a great day yet again! Keep up the good work!
4. My son is age 23. Attends Thornage Hall day services/ care farm. They are amazing!! Attentive, caring, supportive and amazing place to be. He is in his 5th year there and has continued to thrive. I wish there were more places like this for all the other adults with learning difficulties.
5. We have a very supportive SENCO at Reepham High school, but services under a lot of pressure.
6. Our 14-year-old son has got his diagnosis of ASD. Hopefully, he can start getting support.
7. Many more resources available.
8. Coping reasonably well at school and making steady progress.
9. Gradual changes in understanding of SEN in society generally.

10. Professionals I've met really do want to help. I have had a really positive experience. I think it's only getting better too.
11. Nursery support to put ECHP in place. SALT.
12. Child is not at school = better and healthier child.
13. I played the stairway piano for people. Learnt lots + freebies. 😊
14. General support in mainstream schools.
15. Twinkles SEN activities days CIC has opened up an amazing opportunity for me and my children with SEN.
16. My son is at COWA in Kings Lynn and is lucky enough to have a fantastic support worker. All good at the moment!
17. Being placed in the POD (soon to be SRB) meeting some of his sensory needs.
18. Portage is amazing and we managed to find a lovely nursery.
19. She's in great school (Woodfield's, Sheringham) that meet her needs and push her. Short breaks are allowing her to socialise/ interact with others outside school environment.
20. We booked a speed dating meeting with Access through Technology a couple of years ago and were able to get a laptop for our son to use at school which has been a great help.
21. Musical keys – library sensory ukulele. Asperger East Anglia youth club.
22. Twinkle SEN activity days. Days out for SEN families.
23. Routine and clear boundaries. GP support has been amazing.
24. Fantastic provision provided at Chapel Green school. Seamless transition from mainstream. Educational psychology was very to have on input to EHCP.
25. Events like this conference – loaded with resources and information.
26. The FV conference is the only bit of light and inspiration out there. Thank you for giving me the opportunity to come, be nurtured and feel that it's okay to keep fighting for my child!
27. Having a visit to such a valuable conference. Thank you 😊

Bernadette Pallister,
Administration Manager
Family Voice Norfolk
July 2020