

Family Voice Norfolk Conference

Saturday 10th March 2018 at John Innes Centre

Appendix: Data and feedback

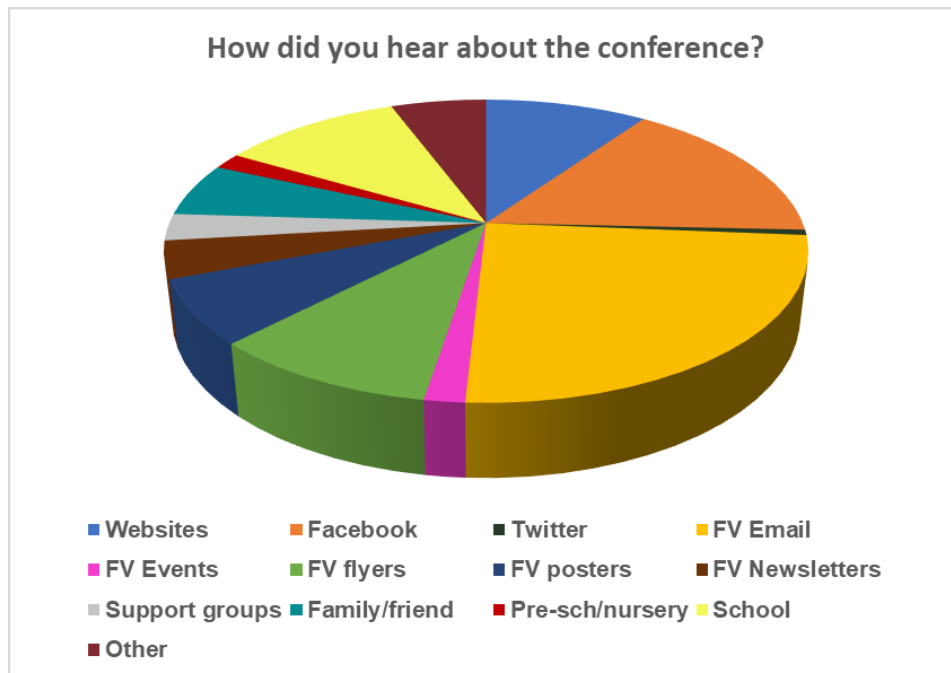
Feedback on Conference from parent carers

Our Conference was attended by 218 parent carers and 101 professionals from across the county as indicated on the map below.



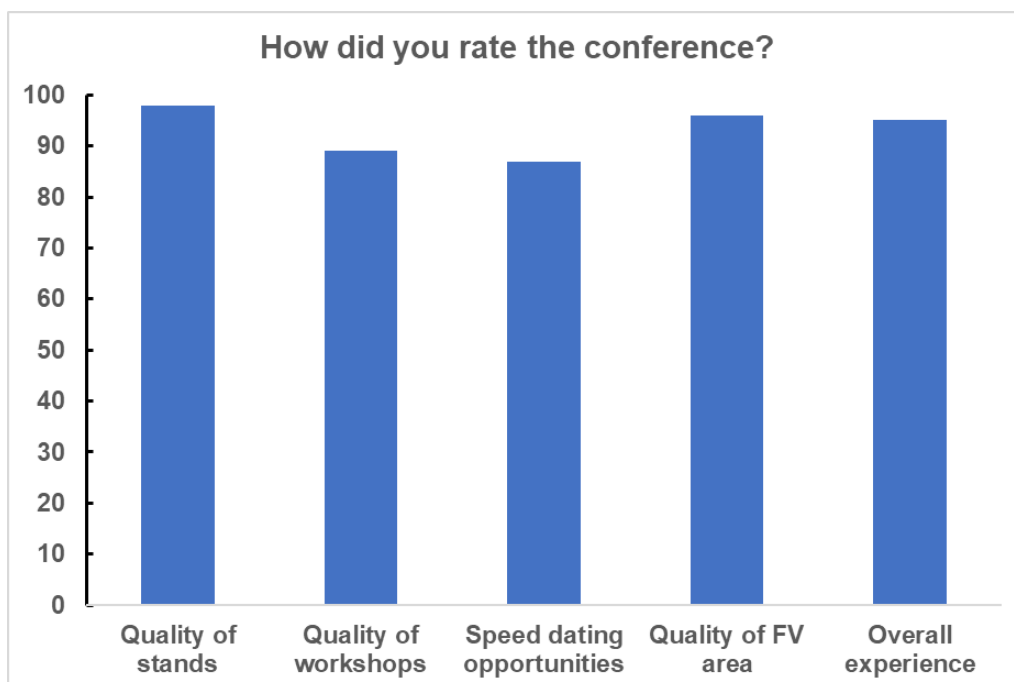
We asked parent carers, presenters and stand holders for feedback on our Conference and for updates on reports that we had submitted throughout the last year on behalf of our members. We had 140 participants fill in our feedback forms, including 28 stand holders. In the following sections are their responses. We have not edited these responses except if we felt that the information given might identify the responder to outside bodies or if a specific individual was 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 speed dating opportunities available at this event?
- How would you rate the Family Voice Link Area 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?

- Meeting lots of people
- A one stop “shop” for information & people of whom you can ask questions
- Speed dating – one to one chat with professionals
- Information all together in one place – chance to talk to others
- Networking and chance to speak to NCC staff
- Different stands and level of information
- SENDIASS organisation
- Emailed the programme out before conference
- Childcare provision excellent
- Wide variety of organisations involved, plenty of leaflets/ information sheets to take home, well organised.
- “Goody bag” with program, notepad etc was helpful
- The SALT talk & focus and understanding of the need
- Thank you very much for arranging “gluten free food specially” – much appreciated
- Sleep East stand and speed dating – helpful advice and tips
- Having access to people from a range of different services
- General information sharing of contacts/ provisions that we were previously unaware of
- Info & Solidarity
- CAMHS, Carers, Speed dating, school/education & childcare
- Childs health stand
- It was helpful to have creche provided to enable me to access the conference
- EHCP workshop
- Food buffet very good
- Talking to Michael Bateman and the SEND Norfolk team
- Key note speaker – high praise.
- Got some information on courses & further education for my 13-year-old son

What could have been better?

- Norfolk county council – key note speaker – not tailored to audience
- Link area as a venue for workshops (EHCP and CAHMS Q & A session) – lots of back ground noise from other stands, children activities, too much light could not see slides.
- The EHCP talk in a proper room
- Communication – no one got back to me in time regarding having a stand
- No programme number displayed in FV link area
- More quiet area spaces for time out
- More stands/ workshop related to those over 18+ looking at PIP & ESA applications, day services/ care farm stands
- People getting up and walking out before Key note speaker had finished
- Please include a Glossary in the FV bag
- Provision for food allergies

- Tables laid out for lunch
- All of it – info, networking, refreshments, parking – everything.
- A little overwhelming for first time people, people were very friendly but needed a bit more direction to help parents
- Workshop on topics such as challenging behaviour strategies, parent support strategies/ practical hands on tips and advice for parents with children exhibiting challenging behaviour
- Ladies loo's ran out of paper in a few cubicles
- Once a place at [the creche] has been confirmed a picture and list of things they could do included so I could have done a story board/visual board for him to reduce his anxiety about going
- Autism specific session
- Local offer website
- Was a little squashed at times
- More ASD stands
- More seating when you first come in – grab a coffee and read programme, presentations need to be less data
- Separate feedback for workshops because if you attend 2 different ones they could be very different in terms of quality and usefulness
- I was disappointed that Autism Anglia and ASD helping hands and Alpha were not at conference.
- If could leave younger children at [the creche provision] and if Speed dating was on for longer.
- More workshops on 18 + issues – supported living, jobs, apprenticeships and internship
- Would be nice to have drinks available with lunch in the same room even if it was just water/squash
- Short breaks workshop
- Speed dating to include Educational Psychology
- Workshop being repeated in the afternoon - as not enough time to go to them all
- Maybe more for young carers – now the family is affected
- A few more stands for education settings
- Representation for Adoption Support/fostering teams in Norfolk
- Parent carer and young carer networks
- Home education networking
- Stand holders not to have bowls of sweets on them as some children behaviours are made worse by sugar and E numbers

What workshops did you attend? In ranking order

- | | |
|---|----|
| • Preparing for adulthood (PfA) | 44 |
| • Reading and understanding your child's EHCP | 33 |
| • SALT | 30 |
| • CAMHS | 24 |

• Local Offer for Children and Young People (LO)	22
• Carers Matters (CM)	18
• Personal Travel payments (PTP)	13
• Health Services Identifying Pre-school aged Children (PC)	8
• Health Services inc. Annual Health Checks (AHC)	5
• Independent Travel (IT)	3

What did you find most useful about workshops?

- EHCP workshop content relevant and well presented
- EHCP workshop information was very good
- EHCP helpful, reading & understanding your child's EHCP
- PfA – very knowledgeable and very informative workshop
- PfA – someone who knew what they were talking about and was prepared to answer questions
- LO – good intro to the new website
- LO – young person page excellent presenter and website
- PfA
- CM – championing the rights of carers

What could have been better?

- IT – informative but no handouts to take away.
- EHCP workshop – area too noisy for workshop
- Talking about individual cases after workshop and interrupting workshop.
- We ran out of time.
- CM – very emotional about the fact that there isn't the support for parent/carers.
- CM – frustration at not being available for parent/carers
- SALT – very basic lesson on what communication is (pointless) only 10 minutes for Q & As.
- SALT explained about service but did not complete presentation.

- PTP – PowerPoint didn't work properly but presenter still presented very well.
- EHCP – hold a workshop on annual reviews, correct provision as Norfolk get away with very poor EHC plans that aren't fit for purpose

Any other comments

- Great conference – don't feel so alone
- Thank you, Family Voice, for bringing this conference together again!
- Maybe do 2 a year now?
- Just more of these days – there is so much to take in and so little time! Sorry – I know it must be a huge headache to organise!!
- The event was extremely well run
- Thank you for a fantastic and informative event. As a parent I have really appreciated all the hard work that has gone into organising this event
- Just keep the event going to make parents aware of what is out there and keep fighting for help and support. Thank you.
- Huge thank you as always FV you are amazing!

General comments about services

We also asked parent carers two open questions when they were "Thinking of your child or young person with special educational needs and /or disabilities (SEND)":

- "What is not working well right now?" for which we had 38 responses;
- "What is working well?" for which we had 23 responses.

We have subdivided the comments around each question into subject areas

Not working well

Education issues

- The Senco at the high school is not listening to me or helping school
- Lack of School places (specialist) provision
- Personal skill support within Norfolk
- Lack of access to funding/budgets for additional support
- Lack of support/funding for play, sensory integration, O/T & SALT therapies
- Having to privately fund most things especially for Dyslexic and then fighting to take issues forward
- Getting my child's complex continence care needs met in mainstream school
- Primary school finds it very difficult to understand child is different at home to school

Health

- Mental health support
- The conduct of the GP saying it's not their responsibility to sign children off sick (this is confirmed by BMA) versus the Short Stay school won't help unless signed off. When your child is unable to attend school for anxiety & depression this is a circle of nonsense you can't penetrate
- Referral not being actioned by the doctors. Having to start referral process over and over again
- Communication from Health re- diagnostic pathways, referrals, appointments not happening & not hearing from paediatricians. Not clear how to get referrals accepted. Long wait times with no advice/info/support
- Getting our young person re-homed. 6 months wait already since re-referral to learning difficulties team and not been seen once yet – despite monthly calls to check still “active”.
- Community Nursing thyroid check overdue and had to get GP to sort out. Not many people know they can ask.
- Disappointed with point 1 services – lack of follow on counselling services for young people.

Social & Emotional needs

- How to meet and make friends but have come up with some ideas for the future thanks to info from the conference.
- We waited over 12 months from referral going to starfish for our 10-year-old child who has become aggressive and hitting, kicking and biting. We finally had a worker come out for 2 visits and then they decided to discharge [our child] as s/he did not fit into their area of support. We have an Early help worker who is amazing and is providing support and help but our child stills need help with anger and thoughts and we are not getting that.

Preparing for Adulthood

- There appears to be a dearth of information about the older age group – say 21 onwards but what happens at 25?
- Where are the jobs for our 18+ year olds!!

Family Voice

- Family Voice Chat meeting – please could some of them be outside of working hours for those parents who work?
- Family Voice Norfolk not doing enough to find out what is affecting children & parents In Norfolk and doing something to address it. We can't see what is actively being done (other than the conference – which is great.)

Working well

Education

- School is really supporting my child
- Sensory therapy does work although expensive!
- Support in main stream school
- Short stay school for Norfolk finally kicked in & is excellent
- Changed school and is receiving more support than in previous school
- After a 3 year long (battle) we are one of the lucky families to have been offered a placement in a SRB
- School support at mainstream school. School have taken on board advice from therapists
- Complex needs school & their support
- School – Mainstream with 1 – 2- 1
- Education is working well – our child is in a complex needs school and we get a lot of support from school to help deal with behavioural issues.
- The school is comfortable, not to mention the toys!
- Home educating – conferences like today's are informative and helpful
- DLA pre-school grant has been used for "one-to-one time" to assist & support my child's speech & language development & social interaction (T.A. Support).

Health

- Our child is receiving help from school councillor for mental health issues and CAMHS
- After 2 years, 3 months our child finally got diagnosed which has reduced our uncertainty.
- Individual professionals that follow through with what they promise. O/T is excellent and departments such as sensory support that have been very supportive.

Support from organisation

- Portage service was amazing
- Good support from post adoption support team (Norfolk).

Information, advice and support

- This Family Voice conference has given me so much help & hope, when I really felt that I was at the end of my rope. Thank you.
- Feeling that there are many more options now than there were in the past – even if I don't know which the best ones for my child are.

Updated feedback from parent carers on our surveys about specific services

Short Breaks

Our members tell us how much they value support through their short breaks/respite care their children and young people receive. We know that when families are supported early they don't fall into crisis and can carry on with their caring duties. It makes a great deal of difference to the whole family's life when they can access the right support. However, the waiting times for assessments, information about personal budgets/direct payments and contracts to start accessing Short Breaks still takes a long time to sort out. There are still a

lot of families in Norfolk who would love to access social care support and short breaks but find the current system /criteria too high and the questionnaire very restrictive and the RAS questions very invasive. Whereas other families have commented on the shortage/ lack of Residential short breaks provision in Norfolk. During the summer of 2017, we carried out a survey of parent carers about Short Breaks. The report based on the survey results was published in February this year. Below are comments from parent carers attending the conference.

Concerns

- Knowing what is going to happen when our child's current respite budget stops in six months' time.
- We finally got a short breaks budget (after waiting 2 years of being given the wrong info)
- Having just been signed off from having a social worker there is no continuity of how you can use your short breaks personal budget. Up to now we could sort things as we go but now we have to know what we will need in the forthcoming year which is not necessarily what we will end up requiring. Back to rigid procedures.
- Short Breaks finally offered us a budget, but I have been waiting 3 months for a DP card. What is the use of that?
- The current RAS questionnaire – concerns over the number of questions and nature of some of the questions (safe guarding) being asked of our families.
- Criteria are still far too high for lot of support services - lots of our children are disabled enough to be on the disability register but not disabled enough for support in many areas of their lives and families are falling into crisis's.
- Chosen not to use medication for ADHD means we have been signed off by Paediatrician. Finding it a real struggle to find someone to give support to our family/our child for his behavioural problems caused by his ASD.
- If you do not have a learning disability you become "invisible" – we constantly fail to "tick the right boxes"/criteria to get any support. At what point will we be in enough crisis to "Deserve Support?" The system already in place and the people out there to work to support are failing a massive slice of the population in Norfolk.
- No residential short breaks available, but very much needed for exhausted parent's.
- Disabilities team slow, don't listen.

Positive comments

- Good services provided – we have been fortunate to get linked families SB and now transferring to Foxwoods.
- I am truly grateful for our short breaks funding which enables us as a family to have essential respite.
- Autism Anglia Adult services Dereham – busy, active and stimulating learning.
- Respite care – Church Green Lodge know our young person well and give them a good time.
- Short breaks meeting our current needs and really helpful coordinator.

EHC Plans

Starting in October 2017 Family Voice Norfolk organised several Family Voice, Family chat sessions around Norfolk on the topic of SEN support and EHCPs. The slideshows, handouts and workshops were kindly delivered by Norfolk SEND Partnership (SENDIASS). Family Voice Norfolk asked parents for their feedback at the sessions and a report was produced

based on this feedback. Here are the comments from the parent carers attending the conference.

- EHCP coordinators telling lies, not meeting legal timeframes and deliberately delaying the EHCP processes.
- NCC lies and illegal policies around EHCPs
- NCC failing children & parents knowingly & preferring them to make complaints rather than put it right.
- Lack of choice & suitable places for good quality school provision for SEND children
- We have applied for an EHCP – the process takes so long and in the meantime our child is in an unsuitable educational placement.
- We don't feel included in the assessment process – we get told someone from EHCP team will call us to answer our questions, but they never do
- EHCP communication and liaison between service for disability support is very poor.
- My child is stuck in a PRU which can only give limited support. Would like to see a plan.
- EHCP review paperwork for child under 5 years, reviewing meeting held in November last year and still no paperwork. Transition review for school in less than 2 weeks!!!!
- Accessing personal budgets – no columns from coordinators, for feedback, no assistance.
- Constantly chasing up professionals and fighting for service that should be provided through their EHCP.
- As soon as a change to EHCP/need occurs or an updating document is required there is huge delays and the LA fails to meet legal duties e.g. phase transfers, review paperwork, placement changes.
- It takes too long to hear the outcome of the panel – 2 weeks from panel to hear – surely with technology parents don't need to wait so long to hear.
- Transition from statement to EHCP very difficult and trying to contact Norfolk County Council employees also very challenging.
- EHC plans – awful, slow, refusal to acknowledge medical letters.
- Once an EHCP is in place it is helpful for schools to have a copy even if there are no changes.
- EHCP not very good/not specific and will take to tribunal if not better at review.

Speech and Language Therapy (SaLT)

Family Voice Norfolk were first made aware that there was parental dissatisfaction with East Coast Community Healthcare's (ECCH) Speech and Language Therapy (SaLT) service when we obtained feedback at our parent carer participation events around the county in October and November 2016. Several issues were again highlighted in the feedback forms from our annual Conference report in Spring 2017. We were invited to present evidence to Norfolk County Council's Health Overview and Scrutiny Committee for their September 2017 meeting. Family Voice Norfolk, therefore, organised an online survey for our members and our report to HOSC was based on the results of this survey. HOSC will be meeting again in July this year when we hope to submit another report to the committee. To gather updated information from our membership, we asked them at our Conference what were their current experiences of SaLT provision. We also had some feedback from the ECCH conference workshop on their service.

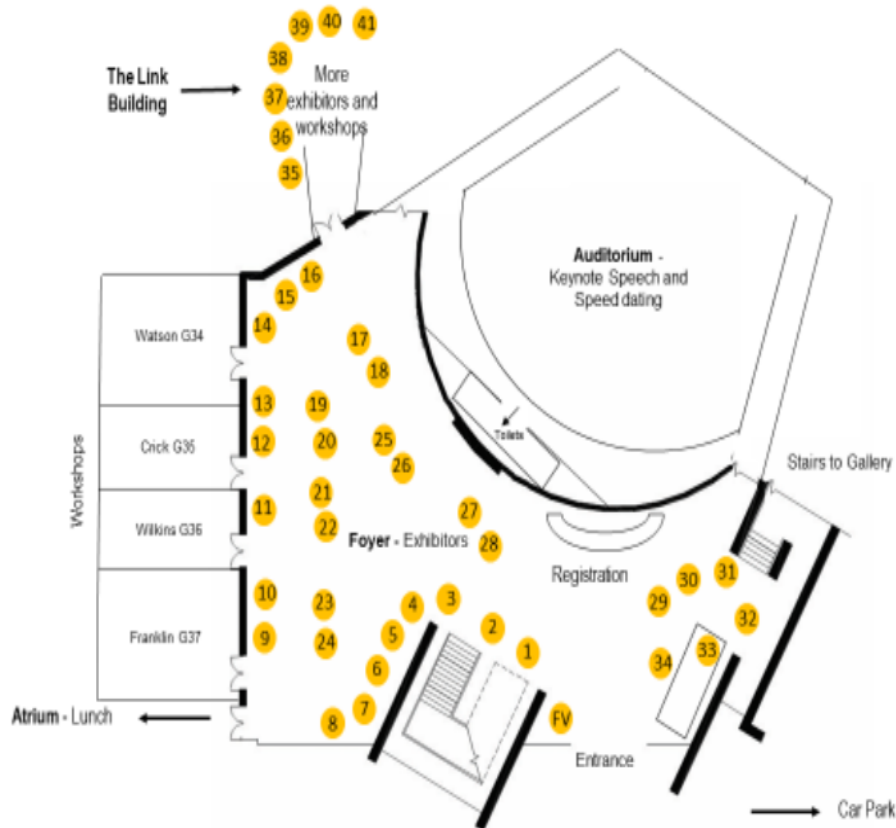
- Problems cannot be resolved in 6 sessions.
- 18 week waiting time for referrals – minimum. Then at least a year waiting on a list for therapy. No prioritising for severe cases.
- ECCH don't provide therapy. Having to pay for private SaLT, which is very expensive. ECCH don't have the resources and say their hands are tied.
- Shockingly bad
- We have already been to mediation and were lied to over SaLT. We have had an annual review and not seen any paperwork/amendment notices yet. We intend to go to tribunal over SALT/ECCH services, short break provision, sensory integration therapy, CAMHS services and transport to school.
- Our child has a mild speech impediment. I telephoned ECCH for an assessment and they tried to do the assessment over the PHONE – not face to face. Our child did not recognise the voice on the end of the telephone and refused to speak. I did not know what was wrong and ECCH then refused him a service – saying he did not meet their criteria. We must pay £35 for 20-minute session each week to private SaLT service – [who] have told us our child speech impediment is correctable but does require therapy and exercises. Conclusion ECCH is not fit for purpose and NCC and CCG are failing children in Norfolk by insisting they keep this contract going until 2020.
- We must pay privately for SaLT and Sensory integration therapy as this is not available to us otherwise.
- I found SaLT really bad, it felt like the lady could not be bother, also my child is coming up to his 4th panel which isn't helpful when trying to get help.
- Need more help with SaLT skills
- Provision and process are everchanging but rarely better than non-existent and shambolic!!!!!!
- There is an extreme lack of speech and language therapy in Norfolk. Not only no actual "Therapy" being provide to our children, but no support for our parents either – "just left in the dark."
- Referral timescales and actually getting therapy very different.
- Going into complex needs school – when does this happen? Our child has achieved their last outcome, need next target. When will we get regular intervention? My child needs aren't being met.
- Workshop gave a very basic lesson on what communication is (pointless) only 10 minutes for Q & As. ECCH explained about service but did not complete presentation.

CAMHS (*Comments from the workshop*)

- If referral to CAMHS has been declined as if not perceived as being in crisis but have a child stating they no longer want to be here, not engaging in school and presenting with aggressive behaviour at home – where do you then go?
- Why is it so hard to get my child referred/help for his anxiety and depression? When his GP is also begging for help on our behalf? Child is stating not wanting to be alive. Already had point 1 and couldn't engage. Not currently at school – where is the support?

Feedback from standholders

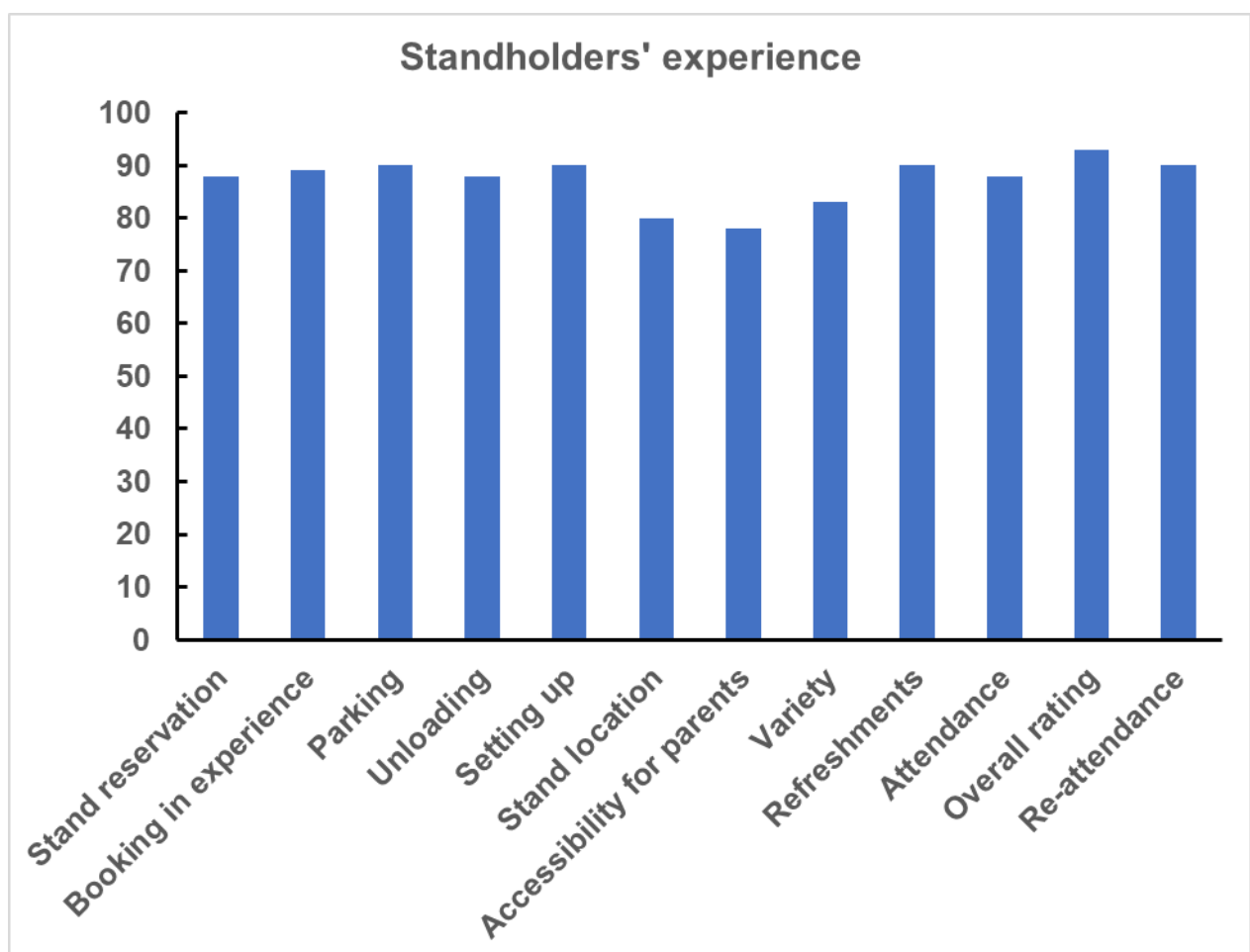
Plan of the stands



- | | |
|--|--|
| 1 Norfolk Community Health and Care | 21 NNAB Young Eyes |
| 2 Norfolk Community Health and Care | 22 Linked Families |
| 3 Home from Home Care | 23 Transition |
| 4 TITAN | 24 Acorn Park School |
| 5 Access through Technology | 25 The Hamlet |
| 6 Access through Technology | 26 Norfolk Portage Service |
| 7 Down's Syndrome Norfolk | 27 Easton & Otley College |
| 8 Children's Autism Services | 28 Healthwatch |
| 9 Autism Anglia | 29 Virtual School Sensory Support |
| 10 Carers Matter Norfolk | 30 Acute Learning Disability Liaison Nurses NNUH |
| 11 City College Norwich | 31 Volunteering matters – CSV Futures |
| 12 Speech and Language Therapy | 32 SENSational Families |
| 13 Local Offer | 33 Norfolk Healthy Child Pathway |
| 14 Norfolk and Waveney CCG | 34 Norfolk Healthy Children & YP's Health Services |
| 15 BUILD Charity and Gig Buddies | 35 Child and Adolescent Mental Health Service |
| 16 Special Olympics Norfolk | 36 Contact |
| 17 Sunbeams | 37 Sleep East |
| 18 Musical Keys | 38 Norfolk Family Information Service |
| 19 Norfolk Library Services | 39 SEND Information, Advice and Support Services |
| 20 Norfolk Register of Disabled Children and Young People, and Specialist Short Breaks | 40 SENDIASS |
| | 41 Family Voice Norfolk |

We had 72% of our stand holders respond to our questionnaire. Their responses (score out of 100) to the following questions are shown below:

- Stand reservation experience prior to event
- Booking in experience on the day
- Parking
- Ease of parking for unloading to set up
- Time allocated for setting up
- Stand location
- Ease of access to stands for parent/carers
- Variety of stands
- Refreshments and facilities
- Parent/carer attendance
- Overall
- How likely are you to want to attend the FV conference again next year?



Individual comments from stand holders

- We were in the LINK – it was so quiet, so we could hear what parents were saying – which we would have struggled with in the main room. We did wonder how many parents did not venture into the link, but it meant we were able to give quality time to those who did.
- The stand location was difficult as parents did not find us as easily this year. Trying to talk to parents when talks were being delivered was also difficult. Delivering a talk at the end of the corridor was extremely hard, it was too bright, and the acoustics were terrible. BUT – still a great conference.
- Stand too close to others – once stands holders placed chairs next to stands very difficult to navigate. Would be nice to have stands get early lunch so they could work through main lunch break. No traffic to stands after 2nd workshop started. Could stands be closed earlier?
- Not quite enough space for stand next to table. We had to slightly block the door to Watson room.
- As ever the whole day is well organised and a great experience. You do need [an] “inspirational” keynote speaker. It sets the tone for the rest of the day.
- Well organised and presented event. Booking easy & quick response to enquiries and needs.
- A great day – lots of enquiries
- Brilliant day thank you, refreshments super and FV team so friendly and helpful
- Thank you for organising this much needed event
- Brilliant day and event. Thank you. P.S. Please can we re -book for next year.
- Organisation was excellent. Stand up the corridor meant it was rather out of the way and much less busy than in main area. Enjoyed speed-dating and received very positive responses for parents attending.
- “Returners” I parent updated me on last years speed dating session, 2nd parent from 2 years ago speed dating and 3rd parent who had complained last year updated me – All 3 parents said things are better!!.
- Excellent event as usual. Afternoon was quiet for stands. By 2:30pm parents seemed to have had the info they were looking for. Well done for a well run event. Will be back next year - a must for our diaries
- Acoustics - noise level hinders conversation
- Well organised and well promoted
- An excellent event to talk and listen to parents. Great to gain feedback from parents with children already at CCN with how happy they are with the provision and how their child is developing. Great to network with other professionals
- Fantastic venue, great organisations, lots of visitors, brilliant food and coffee available all day
- Fantastic Venue as always. Very busy this year - lots of enquires
- Stand was in a good position but just a little impractical as no space for chairs or banners etc
- Great event. Thank you for organising the event
- Thank you for letting me come even though I was late asking. I would love to be kept in the loop for any future events like this

- Keynote address was not pitched appropriately for the audience. Humour was inappropriate and did cause offence. Content was corporate with no opportunity for engagement
- Good event to gather information from. Lots of parents to see and chat to, nice seminar to access
- Need more time speed dating