

Family Voice Norfolk Conference

Saturday 11th March 2023 at the John Innes Centre

Appendix: Data and Feedback

The **eleventh** Family Voice Norfolk Conference was attended by **195** delegates and **127** professionals from across Norfolk.

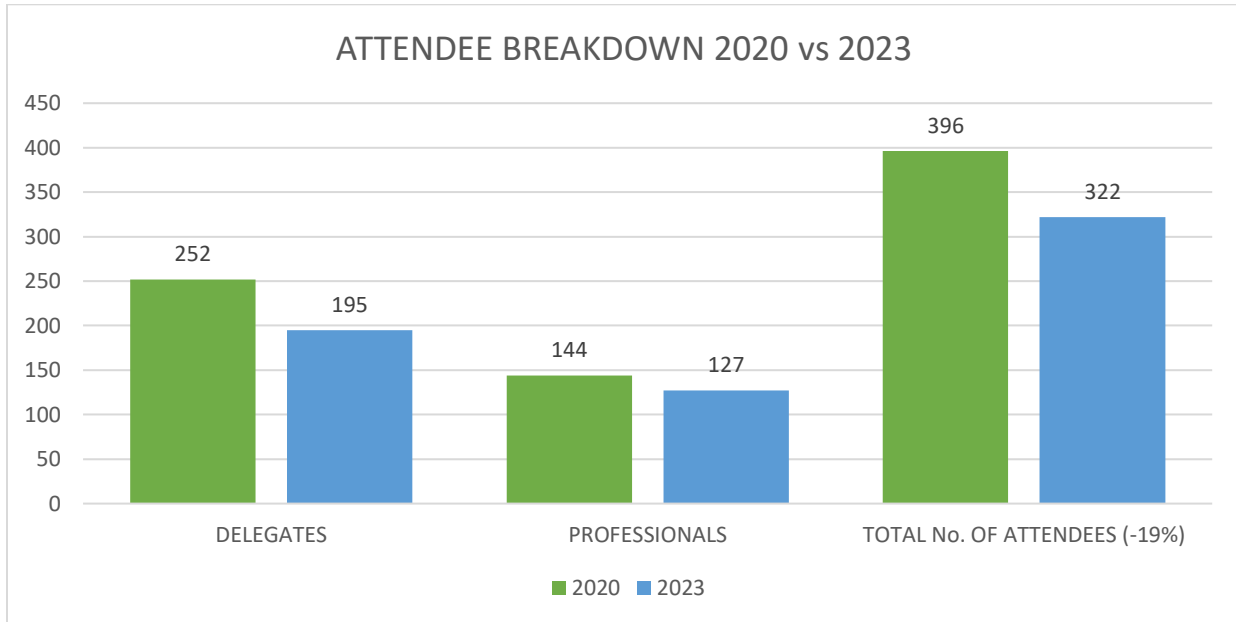
Each year we ask parent carers for their feedback on our conference and for updates on what is working and not working for them at that time. We received a total of **78 (40%)** feedback forms and in the following sections are their responses. We have not edited these responses except if we feel that the information given may identify the person concerned or if specific individuals are named. It is always our policy to anonymise comments from families.

Conference feedback and data analysis:

A total of **37** stands (including FVN) exhibited this year (one less stand than advertised, following an unavoidable cancellation).

Key data:

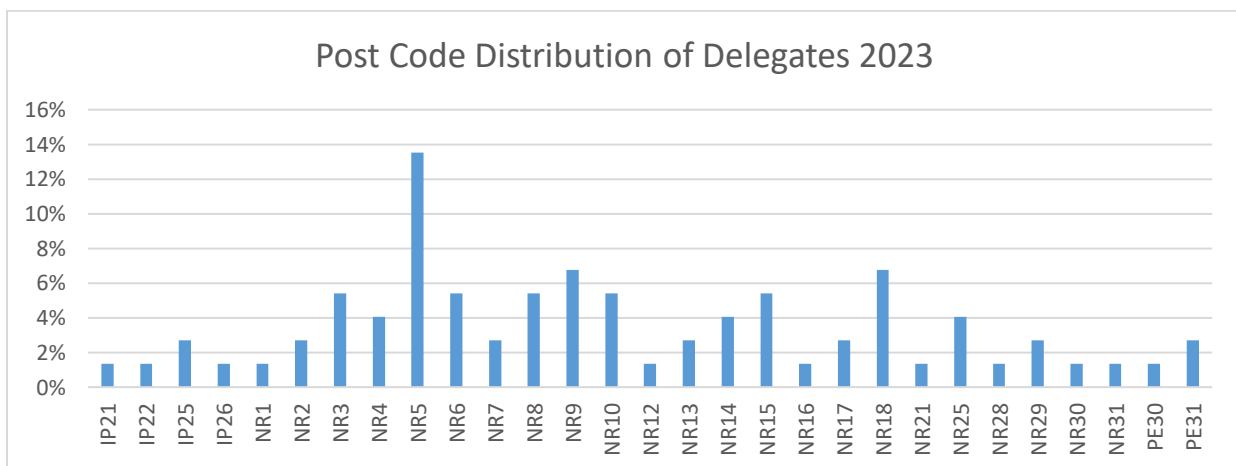
- This was a **reduction of 26%** from the **50** stands that exhibited at the 2020 conference and was due to the “Link” area of the John Innes Conference Centre (JICC) no longer being available for this and all future conferences.
- 2020 saw a total of **252** delegates attending the 10th anniversary celebration and this year we welcomed a total of **195** parents, carers, young people and children; a **reduction of 23%**. For just over **50%** of attendees, it was their first ever time attending the conference.
- In 2020, a total of **144** professionals participated in the conference in comparison to **127** in **2023**; only an **11% reduction** despite 26% fewer stands.
- This gave a ratio of **0.65 professionals to every 1 delegate** attending. In 2020, the ratio was **0.57 professionals to every 1 delegate** attending.
- Therefore, with a total of **322** attendees in 2023 (excluding Family Voice Norfolk staff) in comparison to the total of **396** that attended in 2020, there was an **overall reduction of 19% in attendance**.



We will be looking into ways of increasing the turnout for next year’s conference via earlier advertising, utilising more social media outlets, engaging in advertising collaborations with participant organisations and more promotion within schools/colleges etc.

We asked you:

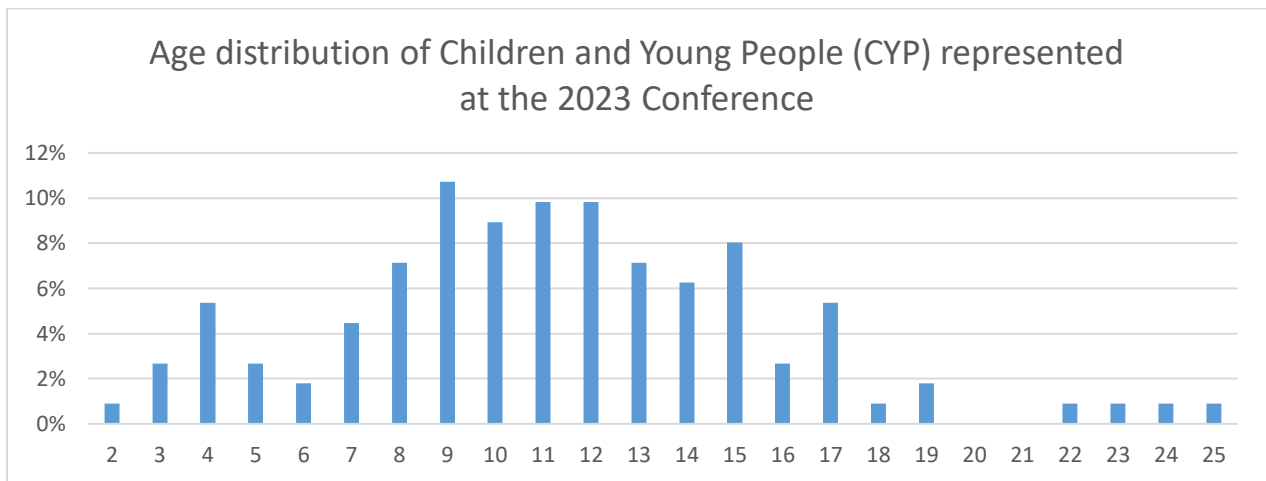
Your Post Code, to help us know how far we reach:



We asked you:

Age of each Child/Young Person (CYP) in your care:

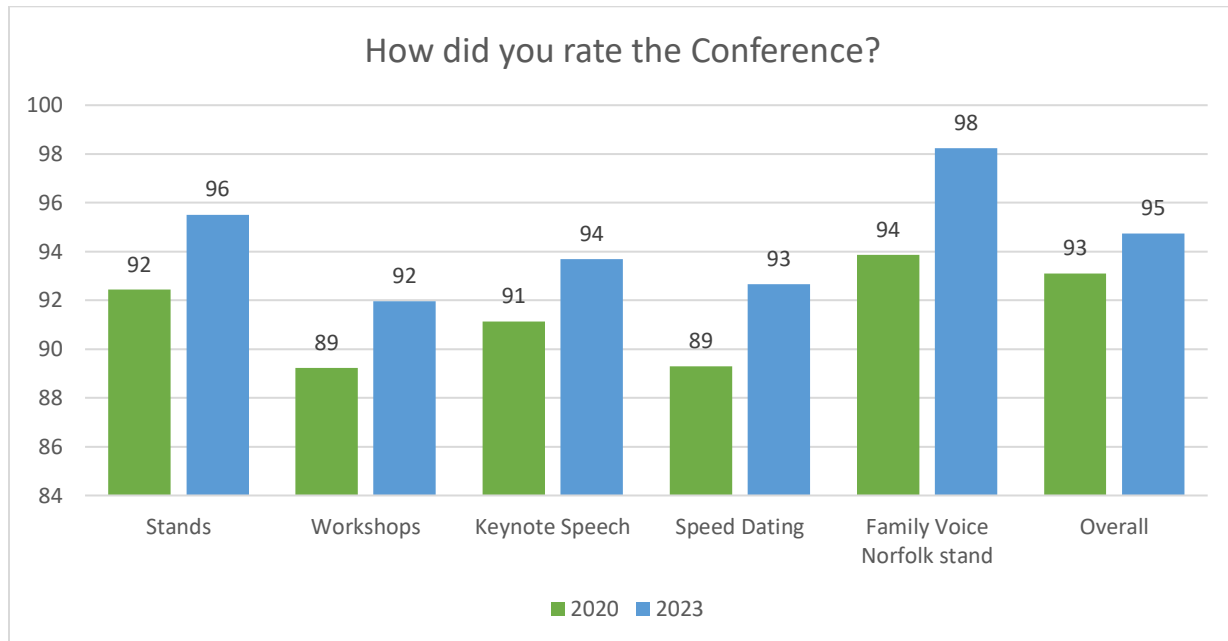
Of those that responded, the largest age groups represented by parent carers were from **9 years to 12 years of age**, with the average age being **11.24**.



We asked you:

- *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 Norfolk stand at this event?*
- *How would you rate your overall experience of this year's Conference?*

The ratings below are for the different activities at the conference in response to the following questions (scored out of 100) and show an **improvement in all six categories** compared to 2020 and an overall improvement rating of **2%** for 2023:



We asked you:

What did you find most useful about this event?

- Information gathering.
- Everything. Before I knew nothing, now I know I am not alone.
- Being able to discuss personal issues with people who are in the "know".
- Amazing Stands.
- Lots of different stands with info.
- Neurodevelopmental conditions workshop.
- Variety of different stalls and a chance to put faces to names.
- Diversity of information, easily accessible, time to talk to most groups or take contact details. Great networking. Spoke to several desks about NHS support, behaviour, support, transition to adult life and Court of Protection.
- Everything! Support from stands and other parents.
- Autism support stands.
- Lots of information.
- Everything! Wow what an amazing place to come!
- Meeting service providers.
- Workshops, Stands, Speed Dating.
- Speaking to professionals.
- Having various organisations together.
- Chatting to people on the stands.

- Lots of organisations and networking opportunities.
- Stands, lectures.
- Interesting, informative, relevant, positive stands. Real help, support and opportunities.
- The stands and opportunities to speak to lots of different organisations.
- All of it : It has been so helpful to be able to speak to people face-to-face again.
- EHCP Workshop.
- Services available.
- Finding out about different services/ contacts available to my child, next steps, specialist college options.
- Meeting some of the professionals, talking to them outside of the "job", finding out about services I did not know about.
- So many useful stalls and lots of knowledgeable people to talk to.
- Information on the stands. Variety of stands. Everyone helpful.
- Speed Dating. Workshops. Access to lots of info in one place.
- Excellent morning workshop: Neurodevelopmental conditions.
- The ability to take time to speak with professionals.
- Face-to-Face. PFAL talk.
- Talking to so many different services and discovering what's available for our family.
- Talking to organisations I had either never heard of or vaguely heard of and hearing what they're all about.
- All the information available.
- Meeting groups.
- The stands - talking to the professionals on the stands.
- All the available resource, support, help.
- The whole event was very helpful.
- Lots of different options/activities available for young people.
- The wide variety of help/information as well as how interactive the workshops are.
- Exhibition - finding all the services in one place is amazing!
- Speaking to professionals/carers.
- Support with EHCP. SENDIASS excellent.
- Really good information and lots of professionals to speak to.
- Speaking to support services.
- Just Norfolk.com. Speech therapist. Neurodevelopmental service. Carers Matter Norfolk. SENDfest.
- All information, health professionals.
- So much information!
- Everything.
- Speed talking to a professional. All the friendly people on the stalls.
- The amount of information that we did not know beforehand that is available locally.
- An amazing event to bring everything together for parents and families. Conversations to resolve issues and share info made possible.
- Talking to "Moving On" organisations from school to college.

- Making connections with services that I wasn't aware of. Speaking to other parents about the challenges of children with additional needs.
- Everything, all the info, advice and support.
- Having one-on-one time to talk with a professional.
- Spoke to new people not heard of. Lots of info to take away.
- More in-depth info at workshops.
- Access to so many key people and organisations in one place.
- Speaking to different organisations at the stands.
- Chatting to services.
- Up-to-date info on what's happening with services.
- The workshops.
- Finding out about services and them being visible and available.
- Sign-posted help, advice and support.
- The variety of support and experts to speak to.
- Workshops and Speed Dating.

We asked you:

What could have been better?

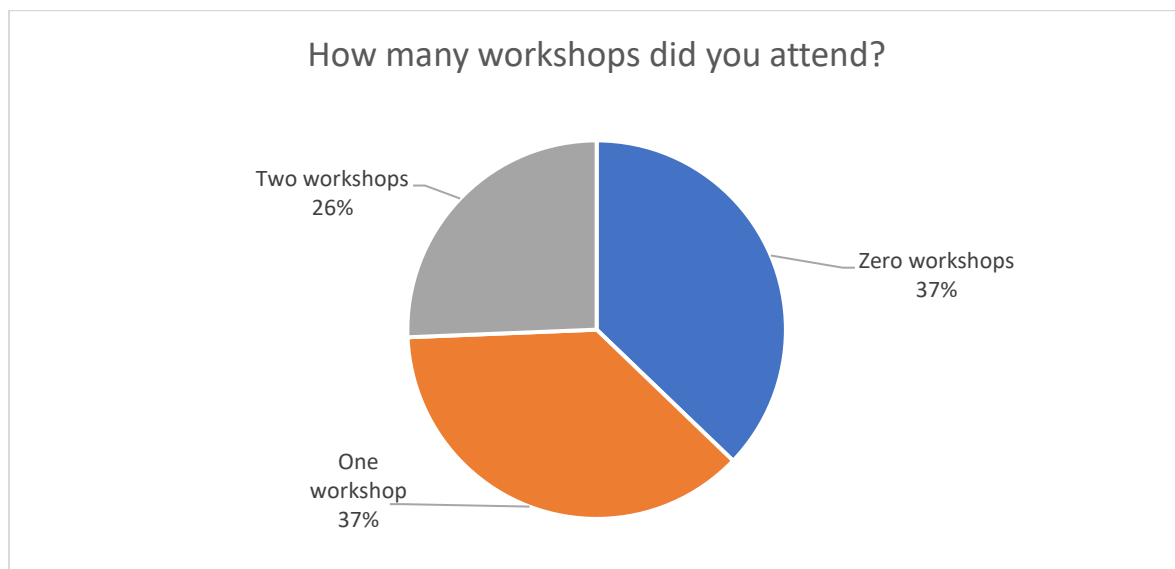
- Seating areas.
- Nothing. Our child is just getting to the age, not much applicable.
- Lunch - some salad/veg type stuff as well as sandwiches would be nice.
- Family Support organisations for families with ASD children (like CONTACT for example).
- Benefits advice stand.
- Obtaining diagnosis advice.
- Signposting for lunch.
- More table surface room at eat at.
- Use of second corridor like previous years so not so intense with noise.
- Smaller event than last time so fewer stands/info.
- More seats to eat, but event was incredible.
- Less NHS info/stands (which is mainly not fit for purpose).
- Nothing - perfect.
- Would be nice to have some services for children of secondary school age.
- Some seating to have lunch - they were very few and far between.
- I think you nailed it.
- Help with sleep issues - there was a stand last time.
- Food - where it can be 5 min between each sitting.
- Extra time in Speed Dating - (so amazing!).

- More loo roll!
- Very noisy in main area. I know you have quiet zones, but can we find somewhere to "deaden" the noise ? I couldn't hear what people are saying.
- Seating area.
- More workshops and face-to-face consultations.
- Time slots for workshops so we can access more workshops.
- More space, as when you're a wheelchair user you can't get through!
- When coming out of the afternoon workshop, stands had already packed away.
- I wished to attend 2 different, conflicting workshops...maybe available to watch later online ?
- Someone from NCC on school admissions.
- Talks, Stands, Keynote Speaker.
- Somewhere to sit at lunchtime.
- Areas to sit down and download or make notes/meet others etc.
- Possibly best to position Musical Keys further away from workshop rooms.
- Musical Keys away from the talks.
- Stalls for lesser disabled children. A lot of vendors only had info on physically disabled.
- Being able to book more than one appointment (Speed Dating).
- I misunderstood how to access one of the workshops and missed out. Helpful staff are sharing slides.
- Put the Speed Dating first, as it wasn't until then that we knew who we really needed to speak with.
- Number the stands.
- Somewhere to sit!
- More space around stalls, ditch the Bell!!!
- Signage to workshops, lunch, different areas could be clearer.
- More seating needed.
- It was a little crowded so unable to hear well. The bell was triggering.
- Seating to eat.
- Not really.
- More space, it was very busy and overwhelming - needed seating available.
- One way system around the stands.
- Seating for eating lunch.
- Better signage outside directing you from the main road.
- More disabled toilets.
- Space for the exhibits as it was a bit of a squeeze.
- Lots aimed at diagnosis or older children. Not so much for 6-13 year olds. I know those are the critical/most challenging points though.
- Accessibility - nowhere to sit down made it really difficult for me. Thankfully I'd brought a drink with me as I was unable to get one in the lunch place and would have choked.
- I don't want to hear things aren't where they should be. Our children need support now.
- Sandwiches quite dry and went into food session 10 minutes after and only limited food.
- Please ditch the bell.
- Clear labelling on where workshops are.

- Bigger venue so not so crowded
- Nothing, just have these more often.
- Not sure.
- I can't think of anything.
- More space.
- Absolutely nothing.
- More space around the stands. More seating at lunchtime (I needed to sit and none available).
- A bit more space around the stands as very busy/noisy. Lunch break a bit too long.
- Targeted support for ASD through teenage years needed (lots of focus on young or adults at event).
- Speed dating filled up so fast. Couldn't get first, second or third choice, but good chat - needs to be for longer.
- Clear signage for each stand if they are for specific group e.g. under 5s, Neurodivergent, parent carer, post 16 etc.
- More slots for Speed Dating, think only 4 isn't a lot.
- More time to go around stands as well as attend talks and Speed Dating.
- More workshops/staggered times to attend more than two.
- More areas to sit, chat, meet with others.
- Workshop on ASD social communication.

We asked you:

How many workshops did you attend?



We asked you:

What did you find most useful about it/them and what could have been better ?

Benefits Entitlements: Greg Lonergan	Advice on benefits: it wasn't what we were hoping for, but still well presented.
	Repeating the Benefits workshop in the afternoon would be really useful - couldn't attend as I was in Neurodevelopmental workshop.
	Confirmation of how to apply.
	Very good.

PFAL Outcomes and employment pathway for young adults: Roger Allen & Gina Whiley (AM & PM sessions)	Practical info for teenage (pre & post) changes. Resources for help with this in ASD children - moving into puberty etc.
	Was not actually relevant to me although did gain some useful signposts.
	Really helpful.

Important things to know about being and keeping healthy: Mark Gower, Jacqui Millard & Jody Fox	Very good, good parent to parent information.
	Useful.
	Workshop got a bit "heated" so overran and missed some of presentation.

<p>Neurodevelopmental conditions: Clare Angell & Kerry Kleinau</p>	<p>Opened my eyes to some of my son's issues that we hadn't thought about.</p>
	<p>Really helpful - thank you!</p>
	<p>Very Informative.</p>
	<p>All good info and for after the session, accessibility of speakers.</p>
	<p>Content wise – fantastic.</p>
	<p>Great.</p>
	<p>Brilliant presentation.</p>
	<p>Very knowledgeable and picked up lots of useful information for whilst on the waiting list for diagnosis.</p>
	<p>Info - lots of services available I didn't know about</p>
	<p>Useful to hear more in-depth info.</p>
	<p>Excellent overview of problems, action taken and future plans/services available.</p>
	<p>This was especially helpful.</p>
	<p>Room too small - very crowded.</p>
	<p>Over-crowded room, could not hear speaker well despite asking. Why didn't you use Conference Hall (<i>Auditorium</i>) as clearly an overwhelming need ? With Covid not resolved & vulnerable - not great!</p>
	<p>Useful to hear more in-depth info.</p>
	<p>A bit too crowded and noisy.</p>
	<p>Good overview.</p>
	<p>Need to say what the waiting time is for expedited list and how they could communicate with parents who are on this list for YEARS with no indication of when eventually their child will be seen.</p>

<p>Big Norfolk Holiday Fun & NCC Short Breaks: Emma van Deventer & Rob Cole</p>	<p>Useful to hear more in-depth info.</p>
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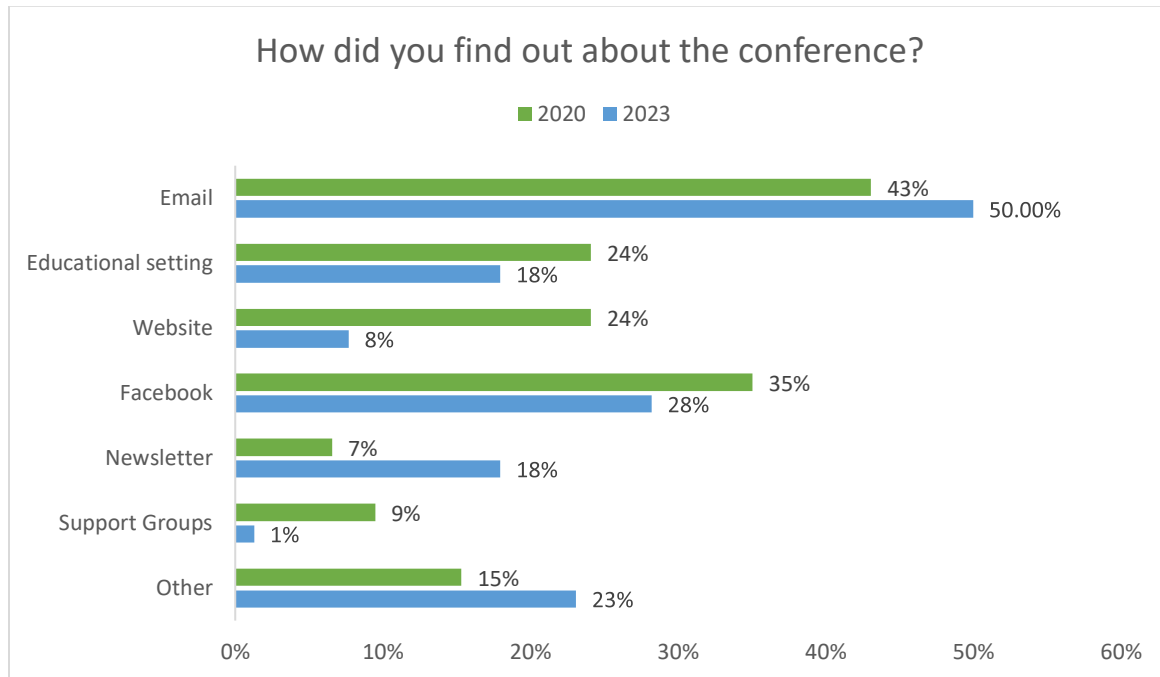
<p>TITAN & School/College Transport: Karl Chapman, Wendy Matsell & Jacky Batchelor</p>	<p>Very useful and informative.</p>
	<p>Useful.</p>

<p>EHCP overview since 2020: Sam McCallum & Amanda Walsh</p>	<p>Learnt so much to help my 7 year old.</p>
	<p>EHCP conversation afterwards.</p>
	<p>Very informative.</p>
	<p>Lots of stats - was good, learning about the law.</p>
	<p>More suited for professionals than parents.</p>
	<p>Good overviews</p>
	<p>Useful was being told what to expect from school in terms of regular meetings.</p>

<p>GENERAL COMMENTS:</p>	<p>Several (workshops) clashed that I would have liked to attend.</p>
	<p>Reminders in workshops to save questions for the end as we were not able to get through everything the speaker had prepared.</p>
	<p>Don't let people in half-way through after started.</p>
	<p>Helpful to have handouts after with websites and phone numbers referred to during presentation.</p>
	<p>People available to talk to after is short.</p>
	<p>Email list could be sent around while presentation is going on.</p>

We asked you:

How did you first find out that this event that was taking place ? (Tick as many that apply)



We asked you:

Would you recommend the conference to a friend ?

Will you attend next year ?

97% of the parent carers would recommend the conference to a friend, **92%** said that they would like to come again with **8%** being unsure.

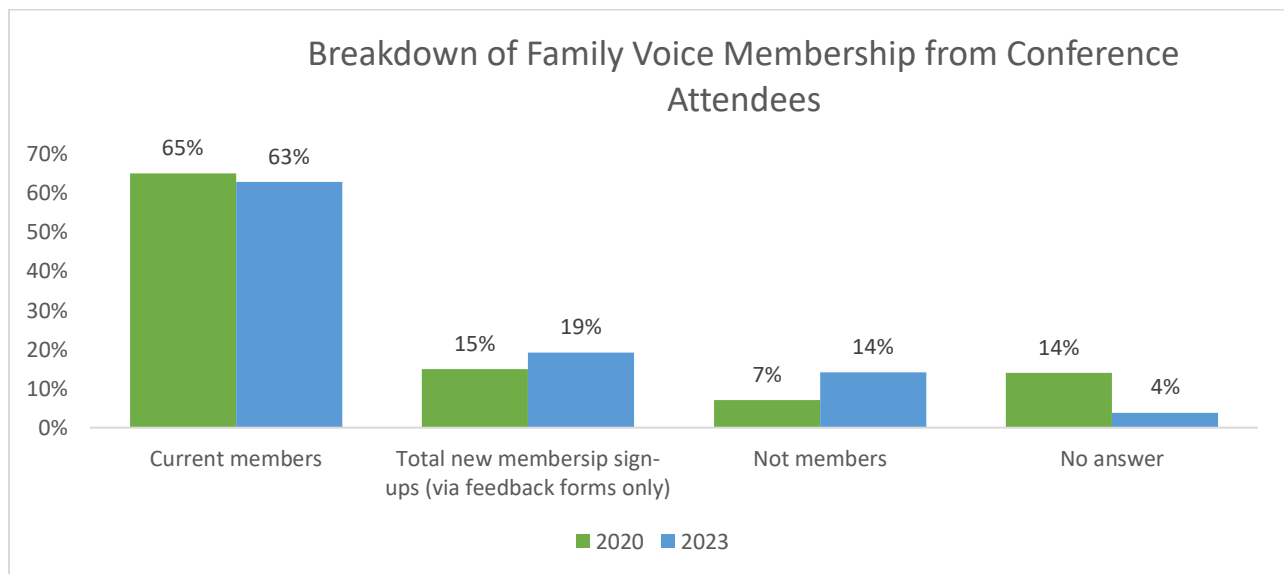
We asked you:

Are you a member of Family Voice Norfolk ?

Parents and carers do not need to be members of Family Voice Norfolk (FVN) to attend the conference, but many chose to sign up afterwards.

From the total of **78 delegates** who completed the feedback forms, **49** were current members, **14** signed up via the feedback forms and **1** had signed up separately on the day, **11** were not FVN members and **3** gave no answer.

An additional 7 delegates completed new membership application leaflets (these delegates did not complete feedback forms) and 4 more joined via the website. This resulted in a total of **26 new membership applications**, **13% of the total number of attendees** on the day.



We asked you:

Any other comments ?

- Thank you so much for this event - it is the **only** time I get to meet people who can help with the issues and concerns I have about helping my children. Such a valuable asset for parents of children with SEND - it's great that so many useful organisations are grouped together.
- Appreciate the time and effort that was invested in hosting this conference.
- Thank You!
- So amazing, such a well-planned day. I finally feel I'm not alone and so much support out there.
- Thanks You!
- Wonderful (Keynote speech). Apologies, only in for the morning.
- Would be nice to have services represented for children aged 12-16. I know that there aren't many out there, but there is such a gap in the market for this.
- Great as always, thank you!
- Thank you SO much!
- Thank You! Wow!

- Lunch was fantastic, plus the free tea, coffee and cookies.
- Thank You :)
- Asperger (High Functioning Autism). Suggestions: Behaviour Management Techniques, info, resources, specific signposting, Thank You. Planning on attending Puffins course.
- Thank you everyone!
- It was a great day - thank you!
- Superb, thank you so much.
- Will bring my child next time.
- Stay Cool :)
- Great day, lovely lunch, fantastic meeting people.
- The whole day has been eye-opening. This was my first time attending and didn't quite know what to expect and it has been wonderful. So much that I hadn't realised was available that I will use/learn more about to help my family. Thank you.
- Thank You!
- Brilliant
- Very nice informative day. 100%
- Accessibility - not easy because disabled parking is so far away - I had to be dropped off. My son was knocked because the stands were so busy, the quiet room was too far away. Lunch service was great because I was given a chair. I feel that more chairs should be provided.
- Very interesting day, also nice to spend time with just me and hubby
- Absolutely thrilled to attend as had no idea on all of the support available locally.
- Wish I had discovered you sooner. Thank you for such a wonderful event. Will bring friend/family member next time.
- Thank you.
- Keep up the GREAT work and thank you!
- A very informative event.
- Great event - very well organised. So good accessing services in one space! So valuable.
- Hard to sort child care so I like to come every other year to keep on top of info without using up too many respite days. Thank you so much for organising this - it's hard to find info if you don't know what to search for. It's invaluable to know these organisations exist.
- Great. Thank you.
- I felt the Speed Dating was the most useful part of the 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? – **10** responses received
- On the Green Card: What *is* working well right now? – **16** responses received

Red Cards:

1. Lack of communication from school. It is a complex system which is hard to navigate. Support services are not well signposted.
2. The school; going around in circles. No-one listens. Lack of communication and support.
3. Fighting for SALT provision to meet needs.
4. Lack of communication between agencies and being made to feel as though I am to blame or not doing enough, without help or support to do “better”.
5. School told us to take our child somewhere else if we weren't happy as they didn't have staff to make sure my son took his medication.
6. Long waiting lists for specialist appointments.
7. Struggling to find any support or advice on cognition and learning difficulties for my 6-year-old daughter.
8. Getting the right help: because my children do not go to school they do not have a SENCO which apparently prevents them accessing diagnoses and support.
9. School saying nothing is wrong, but sensory at home and yet she's on a lot of interventions.
10. Educational setting that is not equipped to handle SEN and the lack of other options locally. Lack of quick NHS services and time for diagnosis.

Green Cards:

1. Good communication within education placement.
2. I was able to access "Right to Choose" for my 16 year old by using Evolve Psychology in Harrogate for ASD.
3. Thanks to the support we found through the 2020 Family Voice conference, our daughter is now thriving in a SEND school and making huge leaps in development. The conference opened the door to all the support we needed from dentistry to fighting through the EHCP tribunal process. THANK YOU!
4. Having the school that helps and accepts my son, while also explaining everything to me so that I can understand.
5. Her school is fantastic and doing so much to support her.
6. I am impressed with the help for the 18 plus age group. I have picked up a lot of useful information that was previously missing for my daughter's care and transition to Adult Services.
7. School will support the student they see without the diagnosis because it is such a long way.
8. SALT have been brilliant and really helpful.
9. My daughter is a happy, bubbly girl who is exceedingly resilient despite her difficulties.
10. It has helped my children by having the right support through nursery and medical professionals and them working together to help my children.
11. Schools have been very supportive and offered helpful suggestions/signposts to get the support needed and put strategies in place in the classroom to help.
12. The ball is rolling and the assessments are beginning.
13. School. Respite care. Transport.
14. The information we have learned from today on all the local support available as we had not been told about the majority of assistance available.
15. The advice from today. SENDIASS has been a great help.
16. Your help! Really appreciate this conference - it has given me faith in humans again and being heard has been amazing.

Family Voice Norfolk Team

April 2023