

Family Voice Norfolk Consultation on Communication and Co-Production

Consultation

Parent carers of children and young people with special educational needs and/or disability (SEND) were consulted via an online survey from 6 to 21 June 2022 about the communication and co-production.

Background

Family Voice Norfolk (FVN) is a collective of parent carers from over 1,370 families across Norfolk and represents nearly 1,800 children and young people with SEND. FVN has been the strategic voice of parent carers working in partnership with Norfolk County Council (NCC) and the NHS Norfolk and Waveney Integrated Care Board (ICB), formerly the Norfolk and Waveney Clinical Commissioning Group (CCG) since 2006. It is funded through a direct DfE grant (administered through Contact), by NCC and by the CCG.

Communication and co-production were identified as being one of the three serious weaknesses by Ofsted/CQC inspectors when they visited Norfolk in 2020. Communication and co-production is about families being able to work together with professionals to achieve the best outcomes for children and young people with special educational needs and/or disability (SEND).

The inspectors said that too often communication with parents and carers was poor. And that too often professionals didn't work WITH children, young people (CYP) and their families. They noted, too, that families often don't feel as if they are being listened to and this makes them anxious and frustrated.

Parent carers were invited to complete a questionnaire online and had the opportunity to include comments on their experiences about communication and co-production and how it is working for families now. The survey ran for just 16 days. FVN received 69 responses.

Key messages

Parent carers

- are more likely to find out SEND information from FVN newsletter (77%), other parent carers (62%) and support groups (59%), rather than from the SEND Local Offer (45%) or SEND Bulletin newsletters (22%).
- find that the most useful source of information about SEND is from support groups.
- prefer to receive information in a meeting with everyone involved present (78%), by email with a named contact (77%) and in conversation with a person in the room (72%).
- prefer to give information about their CYP with SEND in a meeting with everyone involved present (65%), in conversation with a person in the room (65%) and by email with a named contact (62%).
- do not feel that the LA does what it says it will do (68%)
- do not feel that the LA communicates well with them (72%). Only 3% feel that the LA communicates well with them.

- feel that information that they share is not used well (51%). Only 7% feel that it is well used.
- do not have the information and support they need to give their view and be part of the decision-making (49%). Only 7% feel that they do have this information and support.

The LA has recently held online meetings to talk about their achievements since the Ofsted/CQC visit in 2020. The LA uses complex jargon, percentages and statistics to paint an unrealistic picture for parents. These meetings are timed to prevent parents from asking questions at the end.

Never really experienced the best communication in Norfolk for SEN, often very one sided with the LA not in the bit interested in the young person/parents' views, knowledge or info.

Missed timeframe targets, slack communication from EHCP coordinator, no opportunity to discuss options / placements etc.

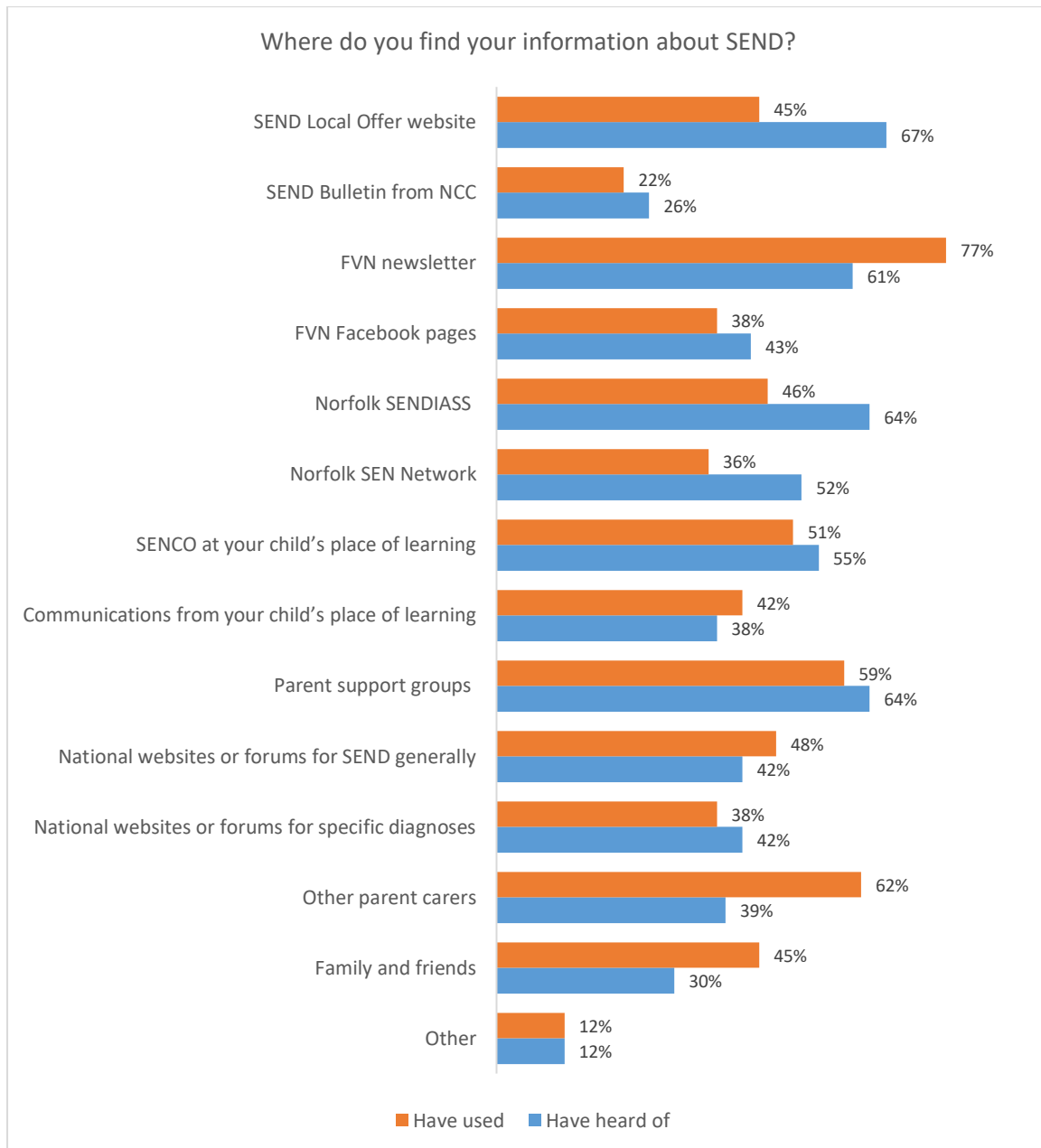
In my experience, dealings with the Local Authority are usually more of a battle than that they are supportive or helpful in any way. They usually have their own agenda and decisions or action taken is more to do with what is an easy option for them, rather than what is right for us and our child's best interests.

I have had to research myself to find all the support and guidance that I've needed over the past few years in battling with the local authority over finding appropriate (or any) education for my son.

Yes, they listen to views but do not always act on them or just have no clue what to do with that information .

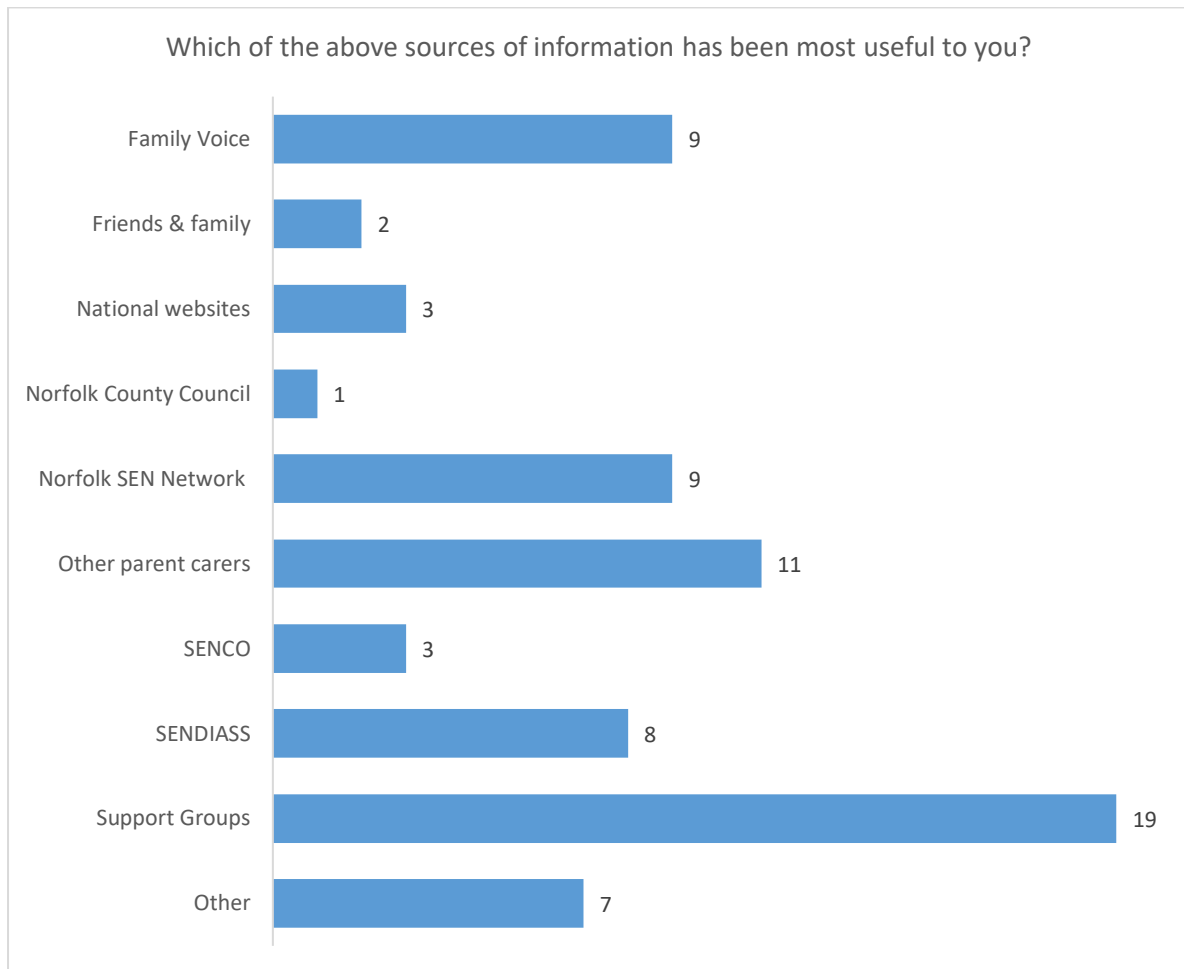
Main findings

1. *Where do you find information about special educational needs and/or disability (SEND)? Below, please tell us which of these you have heard of and, in the second column, which you have used/looked at/spoken to yourself.*



Other included working with children and young people with SEND, Social Services, Short Breaks, and BBC news

2. Which of the above sources of information has been most useful to you?



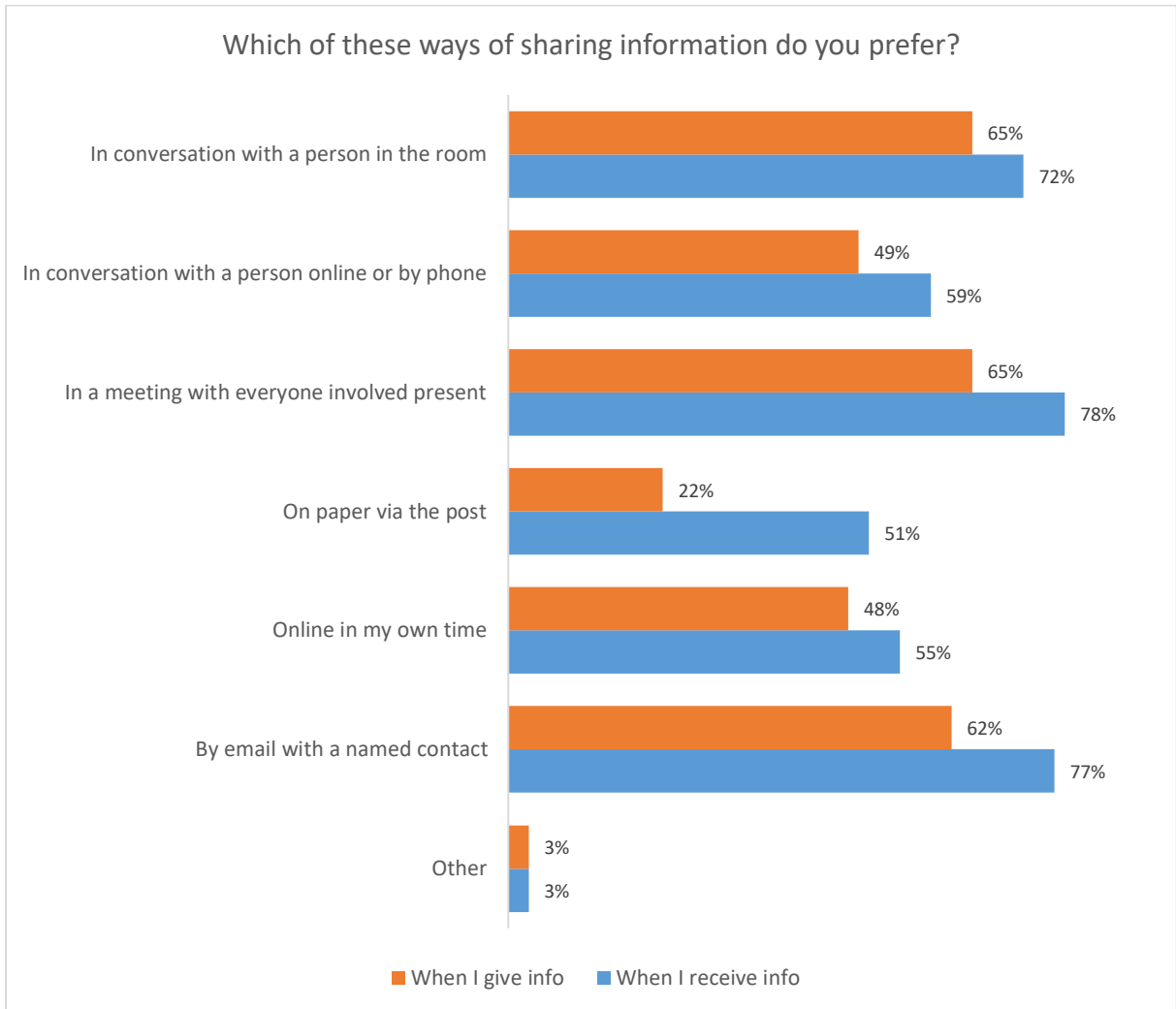
Impossible to choose one as different formats and different information supplied. The power of a 'real person' to talk to is better than any newsletter, website, but only if they really know their stuff. For local information I feel I should mention the Local Offer but was put off that years ago as so arduous to navigate and actually find what I wanted to know. Perhaps it is easier to use now and 'better' but I am afraid I don't have the energy to be disappointed again - unless you can persuade me otherwise!

I haven't had much information or support.

From what I've found out for myself

3. Which of these ways of sharing information do you prefer?

Sharing of information can depend on many things. Parent carers were encouraged to tick as many boxes as they felt necessary.

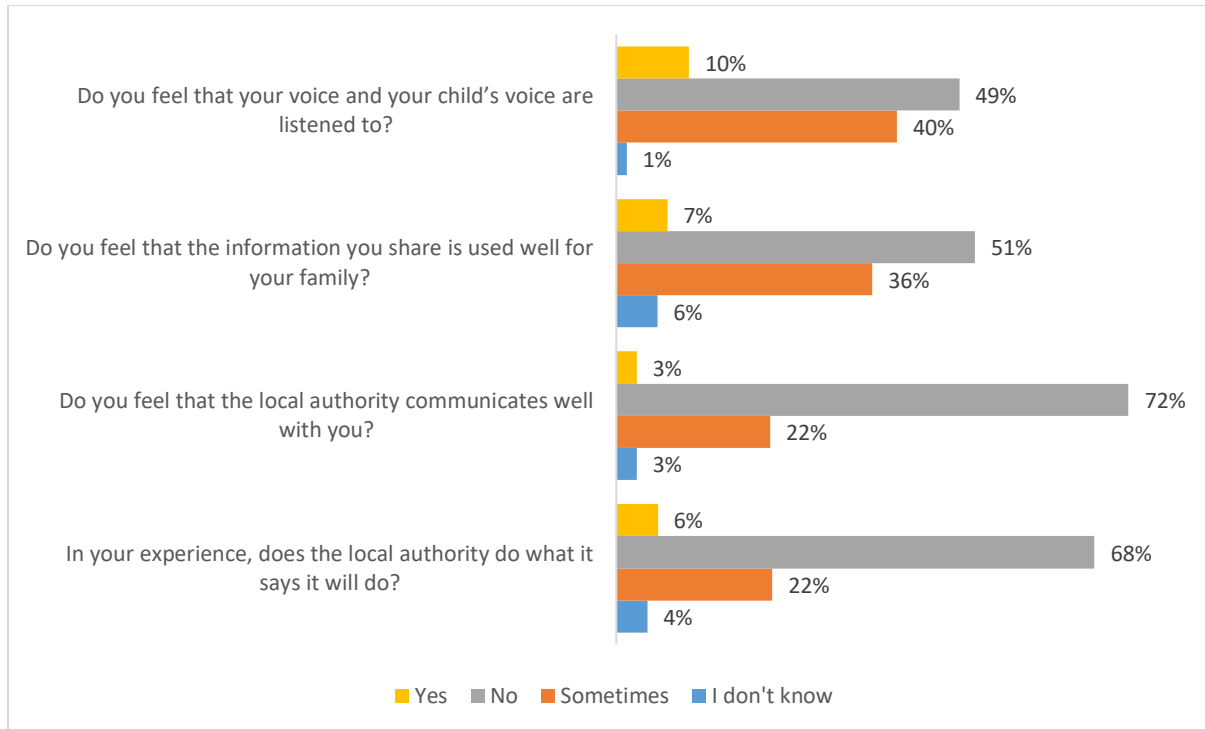


Other comments included:

This question dichotomises the giving and sharing of information, but the best communication is where there is shared information giving and respect. Never really experienced the best communication in Norfolk for SEN, often very one sided with the LA not in the bit interested in the young person/parents' views, knowledge or info.

Don't mind as long as times and distance of location fit in with looking after my young person. Sometimes meetings are so far behind the professionals involved will pressure meeting to happen to their timescale because they have to get something done. This can make life really hard as carer to change routines and accommodate the needs of the professional rather than the person with disability.

4. *The law says that the local authority must take into account the views, wishes and feelings of parent carers and of children/young people with SEND themselves and that they should be part of decision-making about the services they need as much as possible.*



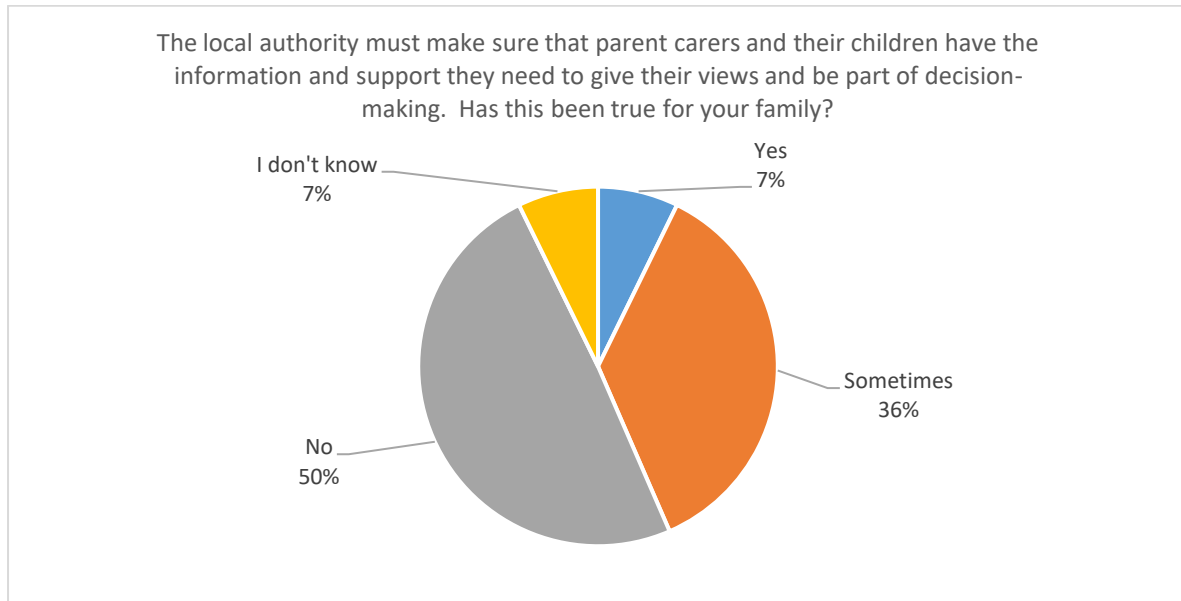
I often receive different information from different members of the SEND team and things are rarely done in the timeframe I am told they will be done. I am always given the same excuse they are busy and overworked

We have had to fight for an EHCP for my youngest child at EVERY stage and will be going to tribunal - Norfolk CC is very quick to spend money on lawyers to object to requests but not spend money on much needed SEN schools.

I have had zero meaningful communication with my EHCP coordinator for nearly a year. I don't even know who they are!

Please refer to Appendix A on pages 9 - 11 for all comments.

5. *The local authority must make sure that parent carers and their children have the information and support they need to give their views and be part of decision-making. Has this been true for your family?*



Now going through tribunal and find the LA are vague with explaining things, disregard feelings and action factual information. They try to scare you away from taking anything further.

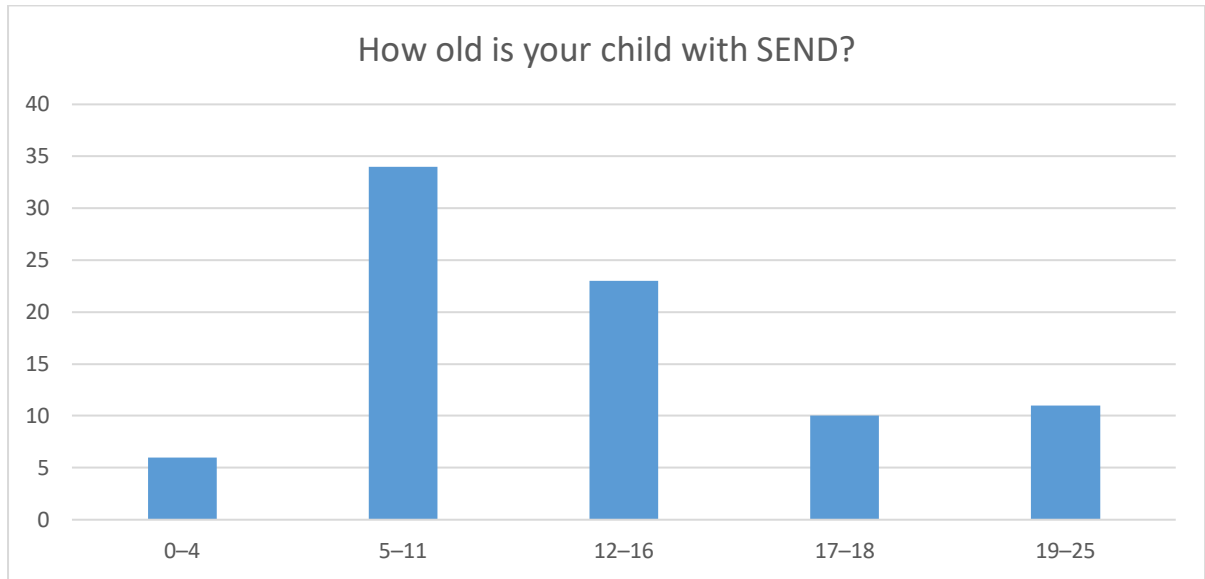
Yes, they listen to views but do not always act on them or just have no clue what to do with that information .

What support? the coordinator doesn't support the parent at all, always sides with the school IF she decided to turn up to the meeting.

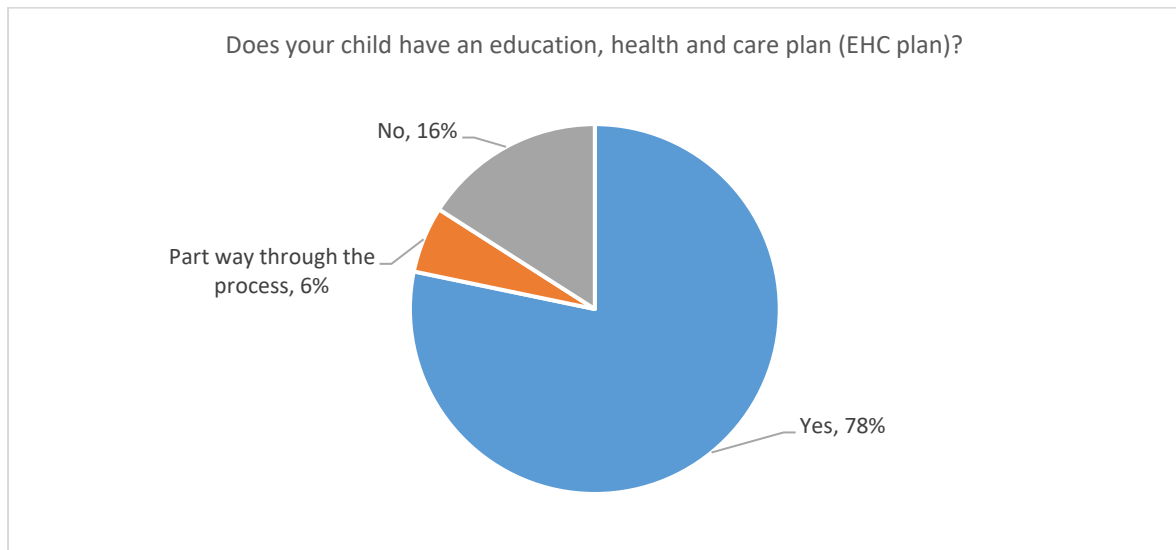
Please refer to Appendix B on page 12 for all comments.

6. How old is your child with SEND?

The 69 respondents have 84 children and young people with SEND.



7. Does your child have an education, health and care plan (EHC plan)?



Appendix A - The law says that the local authority must take into account the views, wishes and feelings of parent carers and of children/young people with SEND themselves and that they should be part of decision-making about the services they need as much as possible.

- Always missing deadlines. Had to get hold of coordinator. Given wrong, misleading and missing information. Everything takes so long .
- As parents/carers we are given strict timeframes in which we have to provide information. Other professionals have time frames which they rarely stick to and there is no apology or penalty for not doing so. The only person who suffers is our children.
- EHCP coordinator has never met us in person, and has never talked to our son. She routinely ignores emails and appears reluctant to undertake any work on our behalf e.g. EHCP review.
- My 10 yr old son has been left in SSSFN since September 2018 after PEX from Mainstream in Early May 2018. He's attended 2x SSSFN provisions. Major safeguarding issues is why we pulled him from the 1st.

The 2nd provision, he has recently been medically signed off (Feb 2022) since not attending end of Jan 2022 for unmet needs, anxiety and mental health- PTSD. Multiple FTE's and failed MTT's.

No input at all from SSSFN or the LA to date. Reports for EHCP ignored of which states my child needs a COMPLEX NEEDS setting, and so twice Refused Offers of placement (by us) to SEMH settings offered by the LA.

The LA have completely ignored and gone behind our back (getting in SEMH schools to assess our son for a place without our knowledge, even on EHCP review day on Zoom and not even a mention that a school was in to assess our son that same day!!!!!!).

The only time we hear from the LA is when they offer an unsuitable SEMH setting for our son. Other than that, all emails I send are ignored (including that to EHCP coordinator).

We have a tribunal date for July represented by Norfolk SEN Network.

Our son has just turned 10 and he is working at Yr1 levels academically. He cannot read or write (has dyslexia), he has a diagnosis of ADHD and has a PDA profile, of which (stated by x2 Ep reports), yet Norfolk NHS will not assess him for ASD (many traits) because of the SEMH type behaviours presented whilst suffering anxiety / PTSD from unmet needs for so long at school.

Our son has been failed by the LA and health professionals since we moved to Norfolk in September 2016, and this needs to end. Our children are NOT numbers or statistics, they are individuals that are being traumatised and damaged by the incompetence and lack of care by the Norfolk authorities.

- I have had zero meaningful communication with my EHCP coordinator for nearly a year. I don't even know who they are!
- I often receive different information from different members of the SEND team and things are rarely done in the timeframe I am told they will be done. I am always given the same excuse they are busy and overworked
- I've never spoken or had communication from our coordinator. She doesn't reply to the schools contact either.
- If by LA you include social services then not so good for young adults
Education communication in our own personal case, has improved but availability of educational provision in west Norfolk for 19-25 most certainly has not.
- In my opinion, LA staff are unable to fulfil their duties being overwhelmed with caseload numbers far exceeding the financial & staffing resources provided for by inadequate central government funding.

- In my experience, dealings with the Local Authority are usually more of a battle than that they are supportive or helpful in any way. They usually have their own agenda and decisions or action taken is more to do with what is an easy option for them, rather than what is right for us and our child's best interests.
- It is often the case that you are constantly passed from one organisation to another and then sitting on long waiting lists or on many occasion forgotten about so you have to constantly chase. when your child becomes 16 services seem to drop away and you never hear from the L.A. It's as if now your child is heading towards adulthood no one want to know. My son is about to turn 18, he was sitting on a waiting list for the preparing for adulthood team for 7 months and every time I phoned I got told he was in the to be looked at pile and they were dealing only with teens that were nearly 18. three weeks before my son's birthday I sent an annoyed email . That day I got a call . Had a lovely chat with a lady and found out things that I needed to get done quickly before he turns 18, like set a card cash bank account up or it be very difficult to do. It's ridiculous . The lady has referred us to some organisations but again there are long waiting lists so he will probably be 19 before he is seen.

All his information should be on file somewhere yet every time we are referred to someone new I have to pull all his info out, photocopy and hand over to new organisation. Surely if you have signed an agreement that info can be shared between organisation then I should not have to do all the admin.

- It often feels like a box ticking exercise.
- Missed timeframe targets, slack communication from EHCP coordinator, no opportunity to discuss options / placements etc. Agreed to assess last July, EP assessment April, still waiting starts year 11 in September!!!
- My daughter was accepted for an EHCP needs assessment on 01/04/2022. It's now 09/06/2022 and there hasn't been any further contact from NCC nor the person dealing with this.
- My son was recently diagnosed with ASD. I recently had to go to an attendance meeting for him. The SENDCO wasn't there, so I felt as if his needs haven't been taken into account and I have been blamed for his attendance difficulties. Family Action are supporting me in finding out exactly what support school have put in place for him, if any.
- Never had the local authority offer help. Had to find out who to help and pushed from one list to another (point one to Map) taking over 2 years then get offered 6 sessions and that's it.
- Not entirely sure what you mean by "local authority". I am thinking of issuing EHCPs. Norfolk is terrible and we have had no contact with EHCP coordinator for years. We feed into reviews but there is no evidence anyone listens and school don't seem to much either. We have to hassle them to change termly learning goals (these are probably wrong at least in part because the EHCP is 15 months out of date and our daughter is only 7 so has moved on significantly)
- Our social worker is very good but her hands are tied by a lack of service provision. For example, following a CETR where the lack of respite was highlighted as the only high risk recommendation a funding panel agreed that overnight respite should be provided at [named provision] and that our son was a priority. However, we were then told there was a 6 month wait. How does a 6 month wait equate to a high risk and priority situation? Various different respite options and help in the home options were then promoted to us based upon availability rather than what would meet the need. This is the wrong way round.
- Particularly on the EHCP I can explain our difficult family circumstances, mum is disabled etc, child struggling with weight but complete refusal to add anything to EHCP to support exercise for example unless its backed by professional report. So where does the view of the parent fit in? If parent in disagreement with school opinion Coordinator will always take schools side regardless of parent and child's views.
- Particularly with EHCP coordinator, communication often unclear, contradictory, takes a long time to receive replies and processes are not explained well - it then is down to me to try to navigate websites etc in my own time to support my 2 SEN children

- So we are about to move to adult service, no PfAL for years and when we did the assessments have taken forever. The communication from the PfAL worker is very poor and the PfAL manger doesn't return calls. We are left very stressed with no idea if our child will remain at his placement and it's the last half term of the academic year. Also the Dols has taken forever., is still not completed and that has held up our application for deputyship.
- Speech provided by county has been appalling and waiting assessment for NDS team has been shocking.
- The academy school that my daughter attends have been very poor. I have relied on SENDIASS and friends to support me and help inform me about SEN.
- The booklet for children to complete is often too simple, my son several times has been given booklets with smiley faces etc. Not all children with SEND have started learning disability and booklets, leaflets, questionnaires etc should be pitched at different levels. He was disgusted getting a smiley face one when he had just been accepted onto A Levels!
- The EHCP coordinator wrote section a of our son's EHCP for us which says it all (we didn't ask for this nor do we think it appropriate). We have been misled by the LA and they often just don't communicate at all. When going through tribunal they only bother talking to you with respect the working document a couple of weeks before the hearing so there are just many more months of silence.
- The LA has recently held online meetings to talk about their achievements since the Ofsted/CQC visit in 2020. The LA uses complex jargon, percentages and statistics to paint an unrealistic picture for parents. These meetings are timed to prevent parents from asking questions at the end. On the ground children, young people and parents feel ignored by the EHCP Coordinator.
- They don't turn out to EHCP meetings and make it harder for parents of SEND children to receive the help and support needed after diagnosis. All children should automatically have a EHCP started and access to ED Psych afterwards to plan the support the child now needs after a diagnosis and that recommendations by professionals are always carried out and adhered to rather than just their advice only. More needs to be done to give our children the lives they deserve.
- Total failure to consult and communicate. I have to chase all the time. Total failure to monitor provision and explain options.
- We have had to fight for an EHCP for my youngest child at EVERY stage and will be going to tribunal - Norfolk CC is very quick to spend money on lawyers to object to requests but not spend money on much needed SEN schools.
- We were asked to decide what school we wanted our child to go to, but they were full of couldn't meet needs so seemed a waste of our time and energy making a decision.

Appendix B - And the local authority must make sure that parent carers and their children have the information and support they need to give their views and be part of decision-making. Has that been true for your family?

Sometimes

- CWD social workers seems to know very little about the transition to adult service. We are feeling very alone in the change coming up, seems like we will be just left to it after having had a social worker for 14 years. So currently in the dark about it all and how the decision to continue funding will be made and who makes it. The local offer gives very little clear detail about post 18 .
- Yes, they listen to views but do not always act on them or just have no clue what to do with that information .

No, this has not been true for our family

- Now going through tribunal and find the LA are vague with explaining things, disregard feeling and action factual information. They try to scare you away from taking anything further.
- I feel completely overwhelmed by the whole process of finding a school and I still don't really understand the whole panel process.
- I find my own support. The LA has not offered it or asked if I need it.
- I have had to research myself to find all the support and guidance that I've needed over the past few years in battling with the local authority over finding appropriate (or any) education for my son. After two years of fighting the LA (tribunals etc.) the result is far from acceptable, with my son being placed in a school 50 miles from home. He is still struggling to transition and is still on a reduced timetable.
- Information is not given. E.g. choosing which schools may be suitable for children, directed to local offer which doesn't give much information. Coordinator not seen in years and poor at replying.
- One of my charges currently has a complaint lodged with County for failing to hear her voice during the birth & ongoing adoption process of her child. Her child has a Social Worker; as a vulnerable young person herself, she does not...

ALL my charges have been serially failed by NCC CS not hearing & understanding their voices throughout their childhoods. Multiple NCS Education & Social Care practitioners have shown confirmation bias to perpetuate systems, processes & policies at the cost of the individuals for whom they're meant to have provided services. If we wrote a book about our shared experiences it would come as no surprise to many others who've experienced similar but a shock to those outside of the systems we're forced to live with.

- The LA have never truly sought my child's views in an appropriate manner. Sending a list of questions more suited to a teenager to a child's school for a teacher to ask a primary school aged kid is not truly involving or listening to children.
- There is no evidence our views feed into the EHCP review process.
- We have had zero support from anybody, even when we have asked.
- What support? the coordinator doesn't support the parent at all, always sides with the school IF she decided to turn up to the meeting.

I don't know

- I'm left in the dark at the moment until my son is accepted into college. We have lived here 3 months now.