

## **Engagement with Parent, Carers and the Voluntary Community Sector regarding the Ofsted / CQC SEND Inspection of Summer 2018**

*Output from consultation event and output the Birmingham SEND Partnership Survey of parents, carers and voluntary organisations in Birmingham.*

*November 2018*

## Section 1 - Executive Summary

At the start of the SEND Improvement work, the board was committed to creating a positive working environment with parents, carers and the voluntary sector. Part of this process is about listening and hearing opinions and then acting upon them.

In order to achieve this goal we asked BVSC to host an online survey and consultation event.

The online survey was conducted on behalf of Birmingham City Council, Birmingham Children's Trust, Birmingham and Solihull Clinical Commissioning Group (BSol CCG) & Birmingham Community Health Trust during the period Oct 10th – Nov 11th 2018.

The survey was promoted by all partners via social media and the newly formed Birmingham Parent Carer Forum.

A consultation event was held Monday 5<sup>th</sup> November. It was attended by over 35 members of the voluntary community services sector, parent / carers and professionals from the partnership.

### Summary of the Survey

The survey was hosted by BVSC and open for 4 weeks between Oct – Nov 2018. 291 responses were received. 151 respondents had children who had been assessed for an Education, Health and Care (EHC) Plan just 25% (43) rated their experience of the EHC process as good or very good.

84 parents gave feedback concerning delays, lack of assistance, complexity and misunderstanding in the system.

Reasons for requesting an EHC plan included – Speech and language delays, Complex health needs, ADHD, Autism, school issues. One parent quoted "I believe my son needs one in order for his school to take his autism seriously"

The majority of EHC Plans (63%) are requested for parents by either health or education professionals.

Nearly 64% of parents experienced challenges with the plan from the 138 detailed comments including refusals, a gap in experiences and expectations, unsupportive, "lots of avoidable mistakes", timescales not being met.

Parents were asked to suggest one change to the EHC Plan process. 167 Suggestions included – better leadership, make it easier, parent & child view taken

seriously, following the lawful process, make it an effective document, online access to progress, listen to us!

60% of Parents rated contact with the SENAR service as unsatisfactory or very unsatisfactory. Parents were asked what changes they would make to SENAR services. From the 140 responses, suggestions included "don't write rubbish EHC Plans", "could try caring", "someone who communicates with parents", "the whole system is wrong", "answer phone calls"

35% of parents had been invited to be part of consultations, and 31% feel sufficiently informed and empowered to engage in the process. Of those 28% feel that their views were listened to and acted upon. Parents were asked to make suggestions about how we could make co-production more possible for parents / carers – from the 109 suggestions, ideas included – "more clear outcomes from input, genuine change", "wider knowledge of consultations", "create more local peer support networks which in turn can help meet local, diverse need", "a genuine commitment to change", "times of meetings – perhaps virtual", "be honest"

Nearly 60% had to tell their child's story more than 5 times to different members of the partnership in the past 2 years with only 15% of them finding it a positive experience.

Parents were asked how we could improve the process – 117 responses included – "reduce waiting lists", "being more understanding and helpful", "read the files", "remove the hostile atmosphere", "I am always fighting for the correct support", "departments should try communicating with each other", Parents were asked their view and how the system communicates with each other – most parents responded negatively.

When asked to suggest how we could improve communications within the services, of the 123 comments received these included "awareness, education and understanding", "where do I start", "parents are experts in their children", "Integrity in following the law", "don't lie to parents", "joined up working", "A complete change in approach", "talking and listening to each other, quite simple really"

119 parents had raised a concern, and 79% did not feel that their complaint had been effectively resolved.

43% children had waited more than 40 weeks for speech and language therapy, 52% of children had waited more than 40 weeks for occupational therapy, 29% of children had waited more than 40 weeks for physical therapy.

During the waiting times 91% of parents stated that they did not feel supported during the waiting period. 39% of Parents suggested that online support would have made a difference during that waiting period, 35% suggested telephone helpline would have helped.

Suggestions for other types of support included – use of voluntary community sector, support groups, workshops, face to face visits. 57% of respondents had visited the local offer website and nearly 60% of respondents stated that it was not useful. Suggestions for improvements included – up to date information, clear language, better signposting, easier to navigate, simplify.

Only 14% of all 291 respondents had children that had transitioned into adult services and of that 14% only 6% rated the experience as good.

Suggestions for improve include – “someone who understands the regulations”, “I am dreading it”, “start earlier than 18!”

The survey aligns to the outcome from the Ofsted and CQC SEND Inspection from summer 2018 and it has been used to populate and inform the Written Statement of Action that partners have been required to produce for Ofsted and CQC.

The SEND Improvement team plan to rerun the survey on a 6 monthly basis between now and June 2020 and 19 of the questions will be repeated in order to inform the impact that the actions from the WSoA are having on the outcomes and experiences for children, young people, families and parent / carers.

### **Summary of the consultation event**

A lively event was held on November 5<sup>th</sup> 2018 at the BVSC offices. Rachel O’Connor, SRO for the SEND Improvement Board set the scene by outlining the activity that the Board was undertaking. Early output from the SEND survey was shared with participants and then we held talking tables on a number of key areas and key messages were identified from the discussions that took place.

1. Parental engagement, satisfaction of parents and co-production. *Key messages – focus on the whole picture around families, meaningful, to build trust, demonstrative actions, join up!*
2. Absence and exclusions. *Key messages – Early intervention with a single point of contact, transitions from primary to secondary to reduce anxieties, better wrap around service*
3. Waiting times. *Key message – updates on progress need improving, look at ways to support parents on the waiting list, Early interventions*
4. Quality of EHC Plans. *Key messages – Robust & Individualisation, trust and confidence, it needs to work for the child*
5. The Local Offer. *Key messages – needs to be accessible, quality information which is easy to find, google search needs to be dramatically improved and the site title needs to be improved.*

**Jeanette Young,**  
**Interim Director of Commissioning,**  
**BCT on behalf of SEND Improvement Board**

## Section 2 - Parent, Carer and Voluntary sector Consultation event

A lively event was held on November 5th 2018 at the BVCS offices. Rachel O'Connor, SRO for the SEND Improvement Board set the scene by outlining the activity that the Board was undertaking. Early output from the SEND survey was shared with participants and we then held talking tables on a number of key topics and key messages were identified from the discussions that took place. All attendees had the opportunity to attend each topic discussion. Each lead recorded the discussions and outputs in slightly different ways, in order to ensure that an accurate record is shared.

### Topics - Parental Engagement, Satisfaction of Parents, Co-Production Professional leads - Jeanette Young & Rachel O'Connor

Wide ranging discussions included

- Information & Advice / Sign posting
- Phone doesn't work / Contact with SENDIAS / SENAR – Better
- SEND Info & Advice Service
- Range of mechanisms to co-produce
- Local Offer – Warwickshire example, dynamic directory of services
- Transition from Junior into Secondary – co-produce with Juniors
- Co-produce resource pack re early years, point of diagnosis
- A number of 'Local Offer' wrong, easy access
- Workshops on what is the pathway, EHCPs, what to expect
- Survey – extend to providers and staff
- Co-production – build back the trust, specific workshop
- Alternatives to EHCP
- Health & Social Care plan
- Employment & Housing input needs to be considered
- How do we join up what we already have – ie Mencap physical exercise programme
- Building trust – quick wins
- Communicate what is happening
- Names to faces
- Repeat the survey on a regular basis
- Representative engagement, working with voluntary sector to reach the whole patch
- Needs an all age consideration
- Regular contact
- Space for families to talk / share specific things they will feel.
- Honest conversations
- Role of advocate, key worker
- Empowerment of key workers, respect for their role
- See 'families' as the profession / experts in their children
- Make change and co-produce to make change for a future generation
- Wider realm of neighbourhoods

Key messages

- Communication between agencies – Multi disciplinary teams
- Joined up story for the pathway, with child experiences
- Focus on whole picture around families – not just school, education
- Joining up what we already have and therefore more efficient with what we have
- Meaningful, to build trust, demonstrative actions

### Topics - Absence & Exclusions Professional lead – Peter Featherstone

A wide ranging discussion on a number of different areas

#### a. Early Intervention

- Single point of contact for CYP&F
- Majority of children with SEND will not have an EHC Plan, but will need support to be put in place early on.
- There is a huge gap in regard to early intervention
  - Having said that though, what would early intervention provision look like?
  - Perhaps teachers / nursery nurses need to be consulted in this regard
- Issues with late diagnosis

- Parent cited the example of her old child who was only diagnosed at 11 years of age, but who had clear and evident needs from an early age
    - Parents need recognition of need at an early age
    - Teachers need to be able to recognise need
      - Example - If a child is excluded at KS1 then teachers need to consider other potential reasons for the child's behaviour
  - Issue in regard to incorrect 'labelling'
  - Teachers need to be able to better understand and address disruptive behaviours as could be indicative of SEN
  - Not so much early intervention, but rather early recognition and *continued* intervention
  - Need to explore other support options for parents, for example family support
  - Consideration of having determined assessment milestones because it is felt that we do not presently have these right
- b. Transition** - From primary school to Secondary School
- Issue in regard to transition from primary school to secondary school and support in both parents and the child with this transition to reduce anxieties
    - Needs to be child centred
  - Primary schools need to actively pick up and address on SEN such as dyslexia rather than pass on to secondary schools to address
- c. Better wrap around services**
- Need better wrap around services – knowing what is out there and pulling it together in bespoke fashion for the CYP
- d. Schools**
- Schools need to adapt their overall approach to CYP with SEN
    - Need to explore potential vocational approaches and not be so GCSE centric
  - Parents need to be able to see their child's capability in different settings – example, what a child is capable of doing at school, but does not display at home ....and vice versa
  - Schools need an alternative solution rather than exclusions
    - Exclusions do not work for the CYP with SEN
    - Need to consider what other support could be put in place instead, to support children in their existing school ahead of reaching a crisis point.
  - Need a single point of contact with a person who understands the needs and behaviours of a child
    - Who recognises a change in behaviour of the child
    - Who knows what works from a SEND perspective and of the alternative approaches that can be explored?
    - This needs to be a familiar person who can move on with a child as they get older
      - For example, in a primary school setting whilst the teacher cannot necessarily move up a year, a teaching assistant potentially could
    - Need an assessment at pre-school stage to pick up behaviours earlier on
      - How do we pick up the 'less severe behaviours'?
  - CYP need bespoke programmes to be put in place that reflect their capabilities
    - Need a negotiated home/school working partnership
  - Are teachers sufficiently trained to recognise and manage SEN? No!
  - Some schools are committed to their SEND pupils, whilst other schools are *"happy to push them out"* / exclude.
    - Parents are being inappropriately pushed to take ill-considered life decisions for their CYP
  - Need to consider the emotional impact on CYP of exclusions
  - Schools do not use praise and reward often enough
    - Lack of empathy and common sense sometimes (indicating perhaps a lack of teacher awareness / training)
    - Lack of open communication between parents and teachers
  - Issues with schools not following up issues such as dyslexia and toileting – of not understanding the signs of SEND

**e. Information, advice and guidance**

- SEND Information, Advice & Support Service is a statutory function which needs to be co-ordinated with health. All parents and young people should have access.
  - We need to boost its effectiveness
  - We need to ensure that an independent point of view is expressed
  - Parents need a resource that they can use to help understand and access services
  - We need better signposting with not just national but local links
    - A clear pathway of what is available
- People need to be able to understand the referral pathways (including parents, teacher, GP, social worker, etc.)

**f. Assessment**

- Parent cited example of 11 year old with need but who has not been given an EHC – appeal / tribunal has been refused twice, and the parent will submit claim again (parent cites there are many more examples of this issue)
  - In this instance, because the child is academically functional, this other needs are not recognised or acted upon
- Issues with SENCO services (*although this comment was not expanded upon*)
- Example cited of a consultant who had written a 2 page report that was completely deficient in regard to stating the children’s needs). When asked to write a more comprehensive report the consultant refused stating that they did not have time. End result being that the advocate had to draft the report and then asked the consultant to sign.
  - Recognition that this is a multi-agency service failure
- More consideration needs to be given to the home environment
  - Need to recognise that the inability of a parent / carer to cope will directly impact the CYP.

**Topic – Waiting Times**

**Professional Leads – Marie Dobinson, Claire Paintain, Dr Doug Simkiss**

Full and lively discussions included;

- CP/DS shared slides on funding – Birmingham stands out as very under resourced. As a result, over the years there has been an increase in thresholds which causes access issues but when people access the service it is good
- There is 8 OT staff for 280,000 CYP in Birmingham (recognising not all will have SEND). Are resources sufficient? There was also talk about combining the Council and Health resources
- Parent cited difficulty getting referral from GP, and a delay with accessing OT service
- Consider more regular contact with families who are on waiting list – families may not need service in the end
- Format of communications – All communication channels to be used
- Difficulty determining the length of the waiting list, but is it possible to give approximate time in the communications (this may be too confusing)
- Can anything be done with cancellation lists and short notice lists? These take time to coordinate but may support moving families up the queue
- SALT, OT and Physiotherapy lists – different speeds
- Is it possible to give people support on the phone? There are contract issues. May need to line up expectations
- Consider videos and other remote techniques to support parents remotely
- Pod casts, online resources
- OT resources – Council and NHS – do different things but can resources be combined for efficiency
- New approach for Joint Commissioning needs to happen now – need to speed up the process of change
- Special schools have increased the size of placements but School nursing has not increased in line with this
- There is an issue with adopting Early Intervention and helping money to flow
- Do parents understand what an OT can do – they ask for them but do they understand what they do, and what help they actually

- need. How do parents understand the services – through Council, GP, NHS
- What information goes out to parents?
- Is there anything else which can be accessed while on the waiting list
- Where is demand for the services coming from – are the right people on the list?
- Parent cited difficulty accessing even though it is in the EHCP. Managed to access through school but it is an independent one.
- Do parents understand what an OT can do – they ask for them but do they understand what they do, and what help they actually need. How do parents understand the services – through Council, GP, NHS
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- Is there anything else which can be accessed while on the waiting list
- Where is demand for the services coming from – are the right people on the list?
- Parent cited difficulty accessing even though it is in the EHCP. Managed to access through school but it is an independent one.
- Midland Mencap raised they have resources families could access for free eg physical activity and physiotherapy – reducing demand
- What other 3<sup>rd</sup> sector resources are there? This is additional resources outside of the council/NHS. Needs a joined up pathway which all these resources can feed into. A portfolio of resources
- There needs to be more innovative ways to understand demand and responses – involving the 3<sup>rd</sup> sector
- Birmingham is under represented in accessing social finance
- Work with Parent carer forum to establish priorities and funding
- Partnership forum
- Access support while on waiting list

#### Key messages

- Updates needed to wording to make it more ambitious
- Need to work more efficiently and look at ways to support parents on the waiting list – but also can we have some more money
- Design changes and communications around the needs of families and CYP / Co-production
- Look at services from start to end, need a single point of contact, speed of improvement to be stepped up. Wrap around services, support for parents on waiting list, Early Interventions
- Consider ways of working innovatively with partnerships and 3<sup>rd</sup> sector to help parents /families access more resources available while on waiting list. Midland Mencap and free physical activity resources an example

### Topic – Quality of EHC Plans Professional leads - Orlaith Byrne

We shared these figures with all groups

- 300,000 children in Birmingham
- 48,000 children with additional needs
- 9300 EHCPs
- 25,000 SEN Support

Discussions included;

- EHCPS – issues → Lack of SENCO support
- SEN Support – transparency & enhancement needed
- Ring-fencing of SEN Support Budget
- Better communication between health and education
- Voluntary sector role / 3<sup>rd</sup> sector
- 0.7% adults with LD in Birmingham have employment (5.6% nationally)
- EHC Support vs “Plan”
- Appropriate & timely meeting of needs
- Too much onus on parents re driving needs assessment
- Needs assessments currently not carved out properly
- School centric process currently
- Enhancing health (+ social care) knowledge of SEN – across the board from primary care up to 3<sup>rd</sup>
- Schools need to be more open to other professionals getting involved
- Effective SEN info and advice Service Birmingham
- SMART goals
- Plan should give a really good snap shot / overview of child, building a picture of them

- Major theme of discussion – SEN needs to work for the child
- SEN support – enhanced, transparent
- Better understanding of SEN
- Appropriate and timely needs assessment
- Communication

#### Key messages

- Enhancement at SEN Support stage – better communication
- Valuing SEN Support?
- Robust and Individualisation
- Building trust & confidence
- SEN Budget – lack of transparency
- Grassroots health information – shared with families
- SEN needs to work for the child

### Topic 5 – Local Offer

#### Professional lead - Philip Bailey

#### Website

- ‘Clunky’ – too many clicks
- English not first language?
- Parents also having learning difficulties?
- Intuitive – easy to find
- Remove jargon and simplify (always!)
- Terrible title (Not obvious on Google)
- Needs an easy route in for new services
- Hard to navigate
- Should hold National Information also
- Social media not used enough (doesn’t matter how good a website is if nobody knows about it)
- Hard to find what was needed
- Searches don’t always find what is actually out there (frequent updates – owned by whom?)
- Needs to be ‘in your face’
- Terrible title – hard to google
- Lack of consistency – changes in offers make it hard to keep up
- Transition to Adults is complex and not always well managed

#### The offer itself

- Needs to be as seamless as possible (e.g. The jump from Yr6 to Yr7 can miss potential traumatic experiences already identified – missed opportunities to support)
- Accessible
- Quality information easy to find

#### Key messages:

- Accessible, quality information which is easy to find
- Make life easy for parents and the organisations supporting them
- Warwickshire used young people in its latest incarnation of the Local Offer – it is easier to navigate video clips etc.
- Needs to be ‘in your face’
- Terrible title – hard to google (again) – push keyword search?

### Topic 6 – Interagency working

#### Professional lead - Philip Bailey

#### Discussions included:

- Equal weighing to all contributions to baseline review
- Who will be scrutinising the outcomes to ensure that they reflect the reality of the young person’s experience (disconnect between professional opinion and ‘real life’)
- Need to avoid making any training a ‘tick box experience’ – needs to be meaningful

- Holistic sharing of budgets is a must if joint commissioning is to be truly effective
- If an organisation is commissioned which offers services that span EHC, there can be 'arguments' about who pays (see shared holistic budget point on previous page)
- Length of time to complete processes (e.g. can mean young person's education in some cases delayed by a year or more)
- Steps - find education placement > arrange travel > arrange care > co-ordinate health?
- Impact of Nursery's need to complete assessments
- Single point of contract used to be offered via FSW – no longer the case. This can lead to delays
- Opportunity to ensure all professionals are always 'automatically' aware a child has an EHCP
- Quality assurance should be embedded, consistent and acted upon by all parties

#### Key message

- Needs true sharing of resources, knowledge, listening and standards
- Inter-agency and teams – delays directly impact Children, young people and families.
- Quality assurance should be embedded, consistent and acted upon by all parties

## Section 3 – The SEND Survey

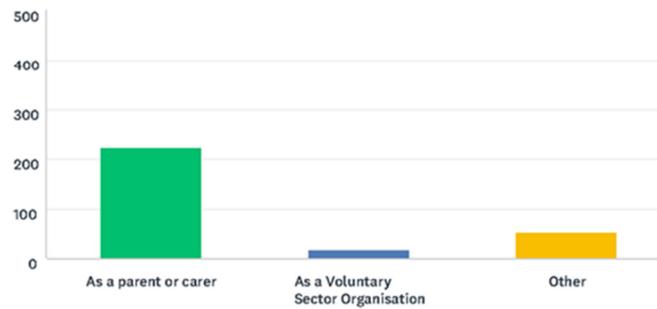
The survey consisted of 36 questions covering a range of subjects highlighted by Ofsted / CQC as areas of significant concern. The SEND Improvement Board intend to use 19 of these questions as baseline questions to enable us to monitor if the work that is being undertaken is having an impact over the next 18 months. Details of the baseline questions is detailed below and this is followed by the detailed survey results.

<b>Baseline questions for April 2019, Oct 2019 &amp; April 2020</b>	<b>Purpose of this question</b>
1 In what capacity are you completing the survey?	<i>In order to ensure that we understand the split between parent, carers and others</i>
3 Has your child been assessed for an EHC Plan?	<i>To understand the number of respondents who have had been part of the EHC process</i>
4 If yes, what was your overall experience of the process?	<i>To gather information about respondents experience of the process and to understand if the changes introduced into the system are making a difference.</i>
8 Did you experience any challenges with the plan?	<i>To gather respondents views of the system's ability to manage respondent to challenges and to see if the changes that are being made reduce the % of people who experience challenges</i>
11 Have you had any contact with the SENAR service?	<i>To understand the number of respondents who have had contact with the SENAR service</i>
12 If yes, how would you rate your overall experience of the SENAR service?	<i>To provide the opportunity for respondents to tell us about their experience of engagement with SENAR and to demonstrate that the system changes are making a difference to the experience.</i>
14 Have you ever been invited to participate in parent consultation?	<i>To understand the number of parents who are invited to participate</i>
18 In the last two years how many times have you had to tell your child's story within the partnership?	<i>This issue was identified by Ofsted / CQC as an issue. The response to this question helps us to understand the problem.</i>
19 What was your overall experience of telling your child's story?	<i>To provide us with an understanding of how parents and carers feel about telling their story.</i>
21 To what extent do you feel that different parts of the partnership have communicated adequately with each other in relation to your child? For example, do you feel that Health communicated with Education and vice versa?	<i>To understand the concern rose by partners and to track if the situation is improving following the actions being undertaken by the SEND Improvement board.</i>
23 Have you ever raised a concern?	<i>To understand the % of parent / carers who have raised concerns and to identify if we have an improving trend.</i>
24 If yes, was your concern effectively resolved?	<i>To understand if our actions are creating an improvement.</i>
25 If your child was referred for speech and language therapy, please tell us how long you waited for the appointment?	<i>To understand the parent / carer experience of waiting times.</i>
26 If your child was referred for occupational therapy, please tell us how long you waited for the appointment?	<i>To understand the parent / carer experience of waiting times.</i>
27 If your child was referred for physical therapy; please tell us how long you waited for the appointment?	<i>To understand the parent / carer experience of waiting times.</i>
28 While waiting for appointments, did you feel supported by the partnership?	<i>To understand how parent / carers feel about the waiting time experience and then to judge if the actions that we are taking have an impact.</i>
31 Have you ever visited the local offer website?	<i>To understand the % of parent / carers who have visited the local offer website.</i>
32 If yes, what did you think of it?	<i>To ask parent / carers their view of the current local offer website and to be able to judge if our actions have had an impact.</i>
34 Have any of your children transitioned into adult services?	<i>To understand the % of respondents whose children have transitioned into adult services?</i>
35 If yes, please rate your experience	<i>To understand parent / carers views of the experience and then be able to judge if our actions are having an impact.</i>

## Detailed survey results

### Q1 In what capacity are you completing this survey?

Answered: 290 Skipped: 1



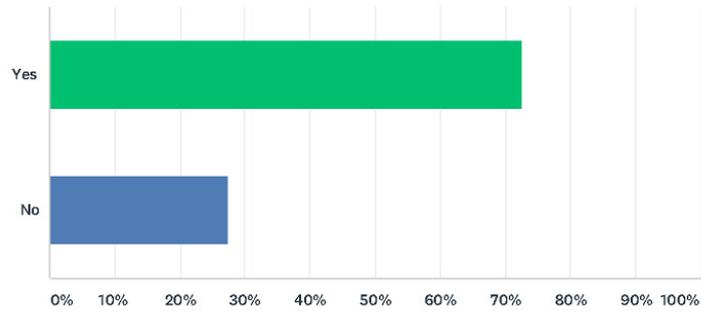
ANSWER CHOICES	RESPONSES	
As a parent or carer (1)	77.59%	225
As a Voluntary Sector Organisation (2)	5.86%	17
Other (3)	18.97%	55
Total Respondents: 290		

#### Q2 If other, please specify below.

1. Doctor, member of NHS, health visitor, nurse
2. Advocate for disabled adults including parents and carers of children with SEND
3. Professional
4. Local Government Officer
5. SEN teacher / SENCO
6. Consultant Community Paediatrician
7. Autism Family Outreach Worker

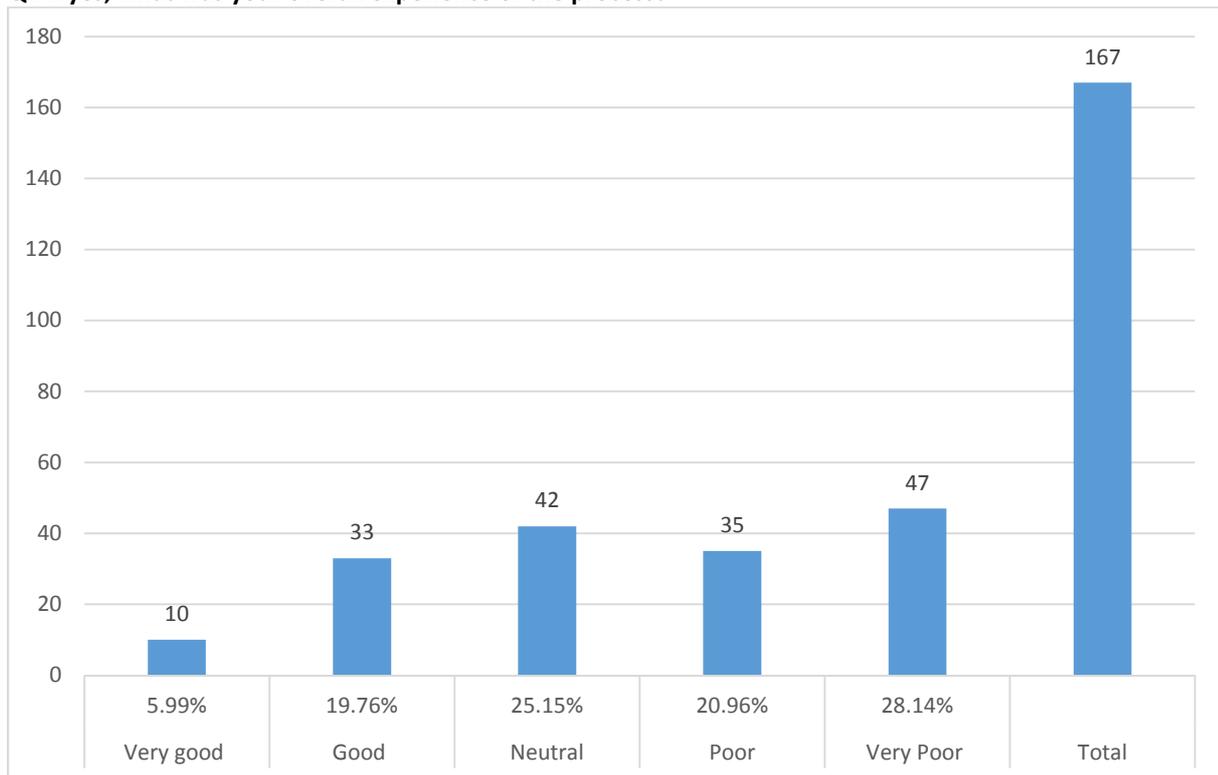
### Q3 Has your child been assessed for an EHC plan?

Answered: 208 Skipped: 83



ANSWER CHOICES	RESPONSES	
Yes	72.60%	151
No	27.40%	57
<b>TOTAL</b>		<b>208</b>

### Q4 If yes, what was your overall experience of the process?



**Q5 If no, please provide details below**

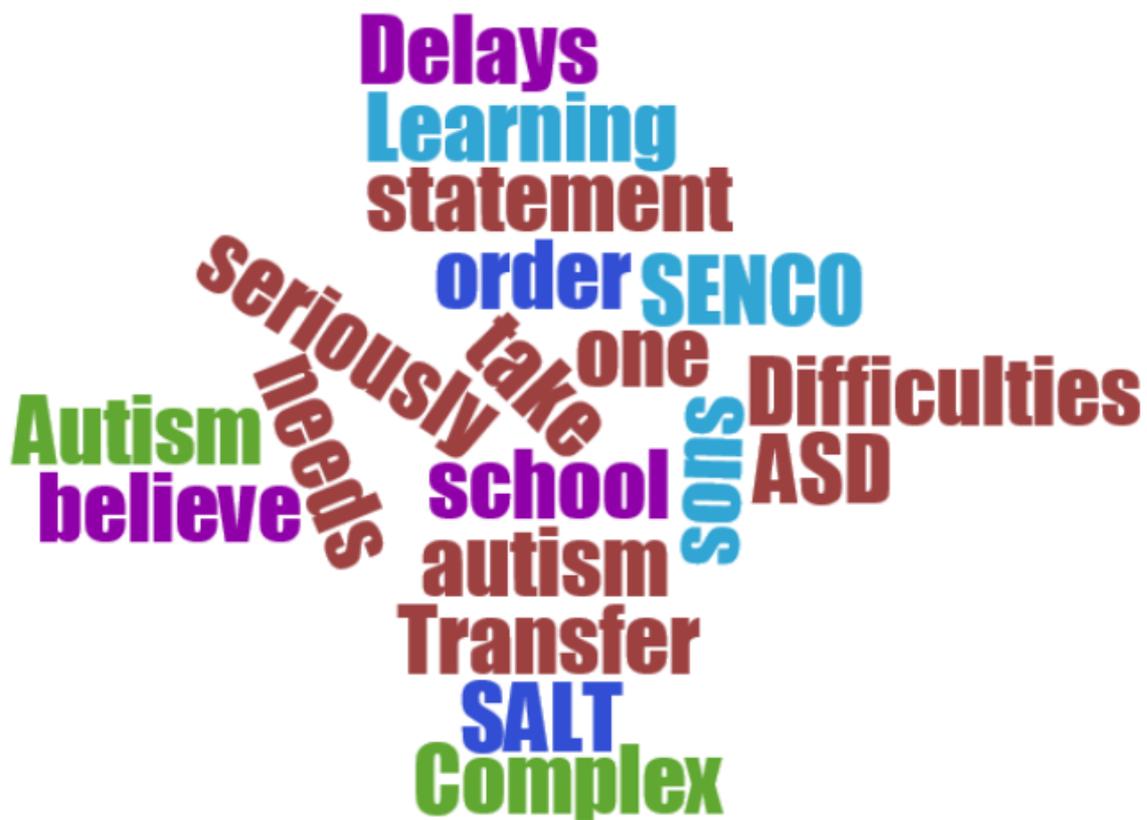
Full narrative is available in appendix A

Key words from the narrative

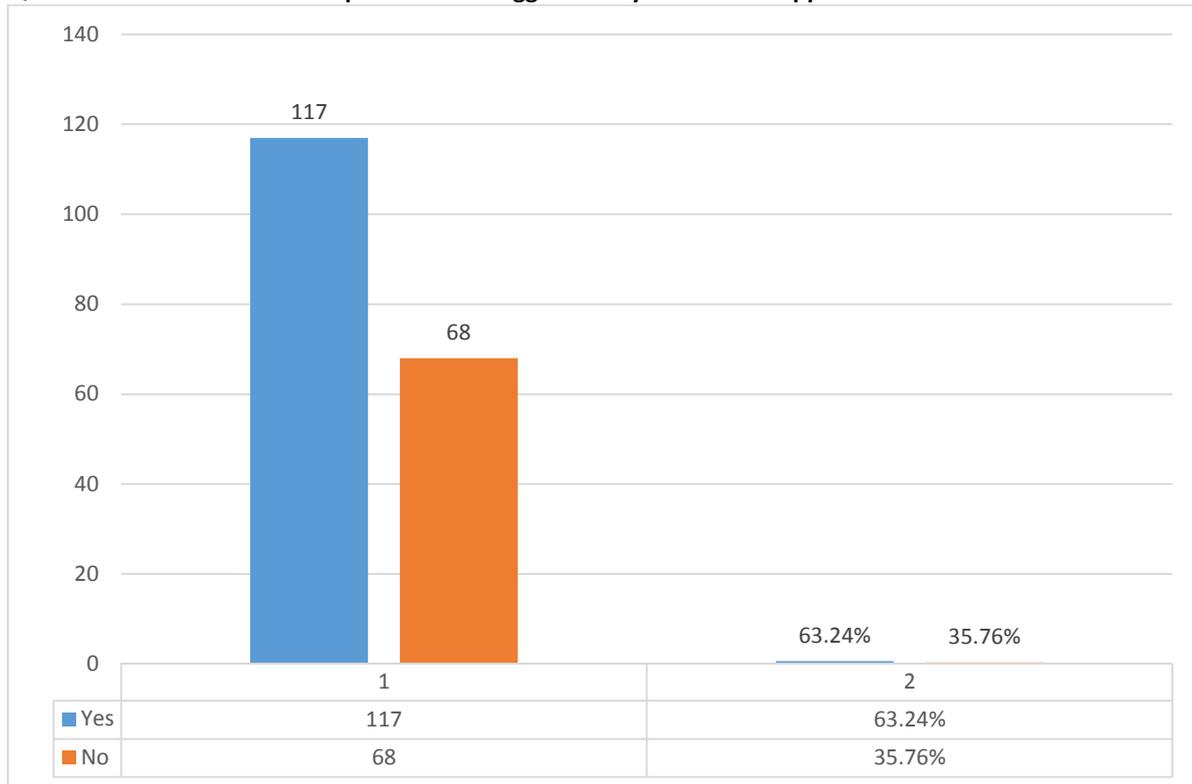
- Help
- Assistance
- SENAR
- Delays
- Complex process
- Refused

**Q6 What were your reasons for requesting an EHC Plan?**

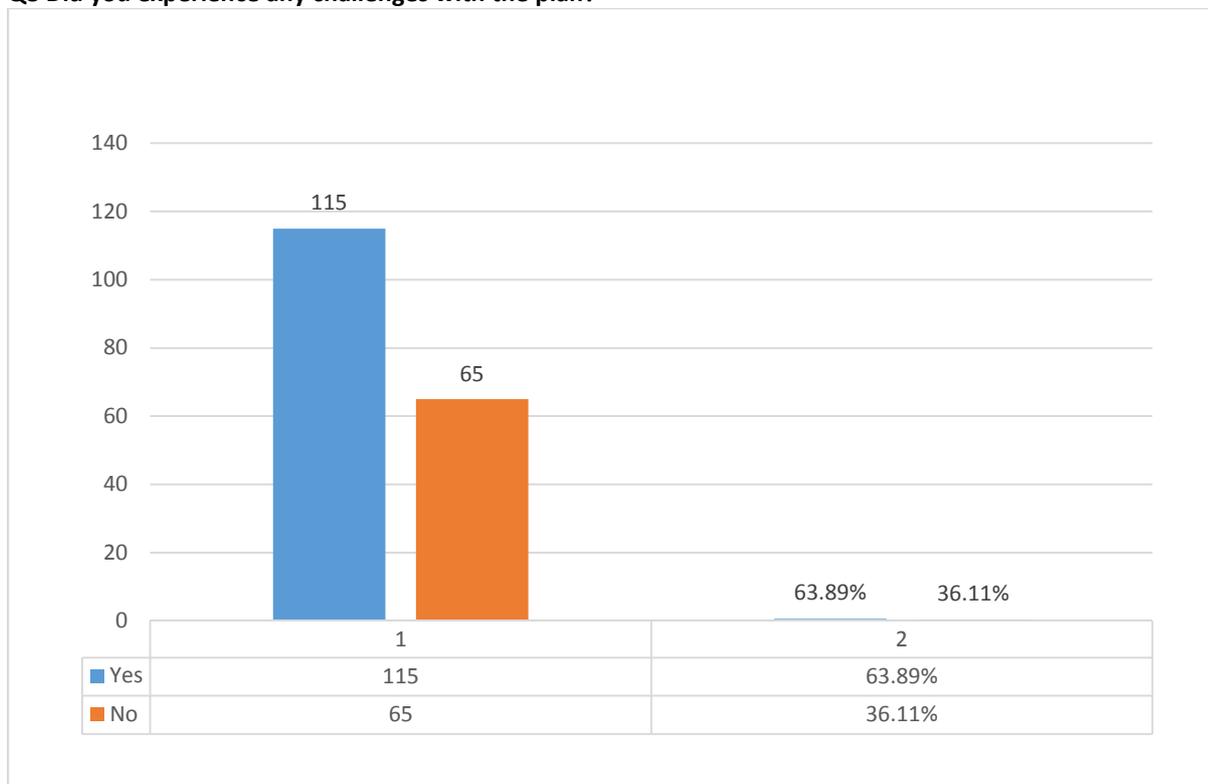
Full narrative is available in appendix B



**Q7 Did a health or education professional suggest that you make an application?**



**Q8 Did you experience any challenges with the plan?**



**Q9 If yes, please gives us brief details**

Key words from the narrative

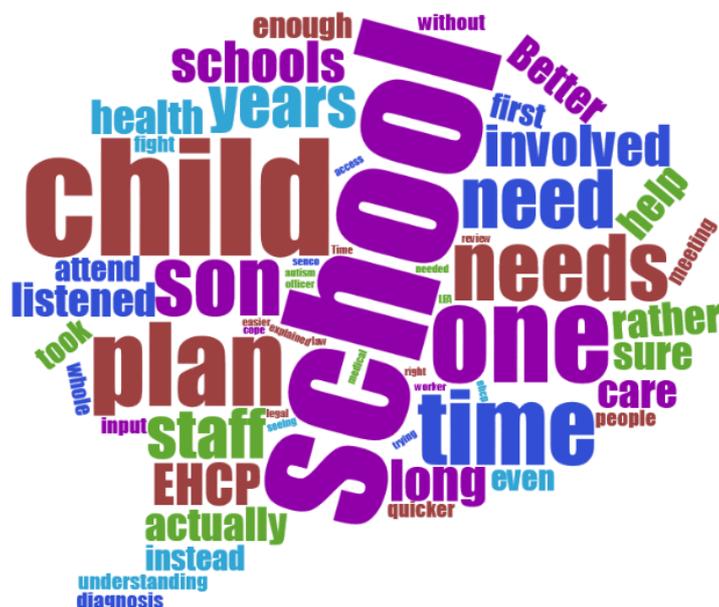
Full narrative is available in appendix C



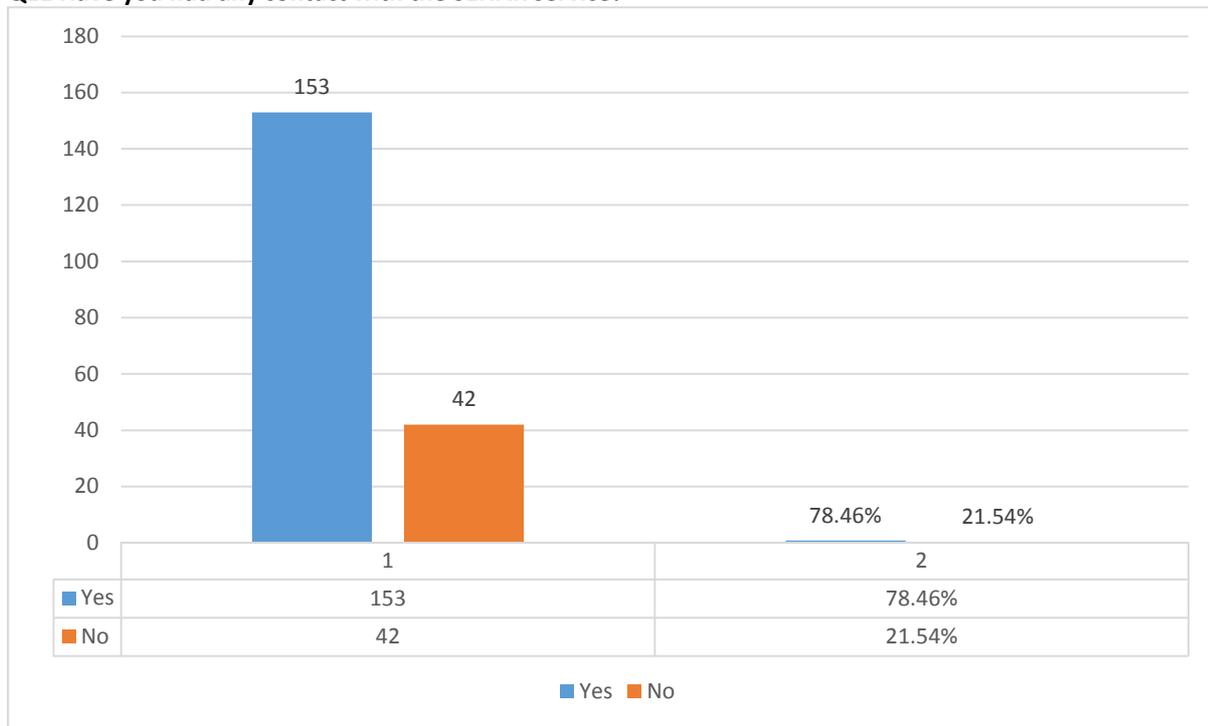
**Q10 if you could have changed one thing in relation to the EHC Plan process, what would that have been?**

Key words from the narrative

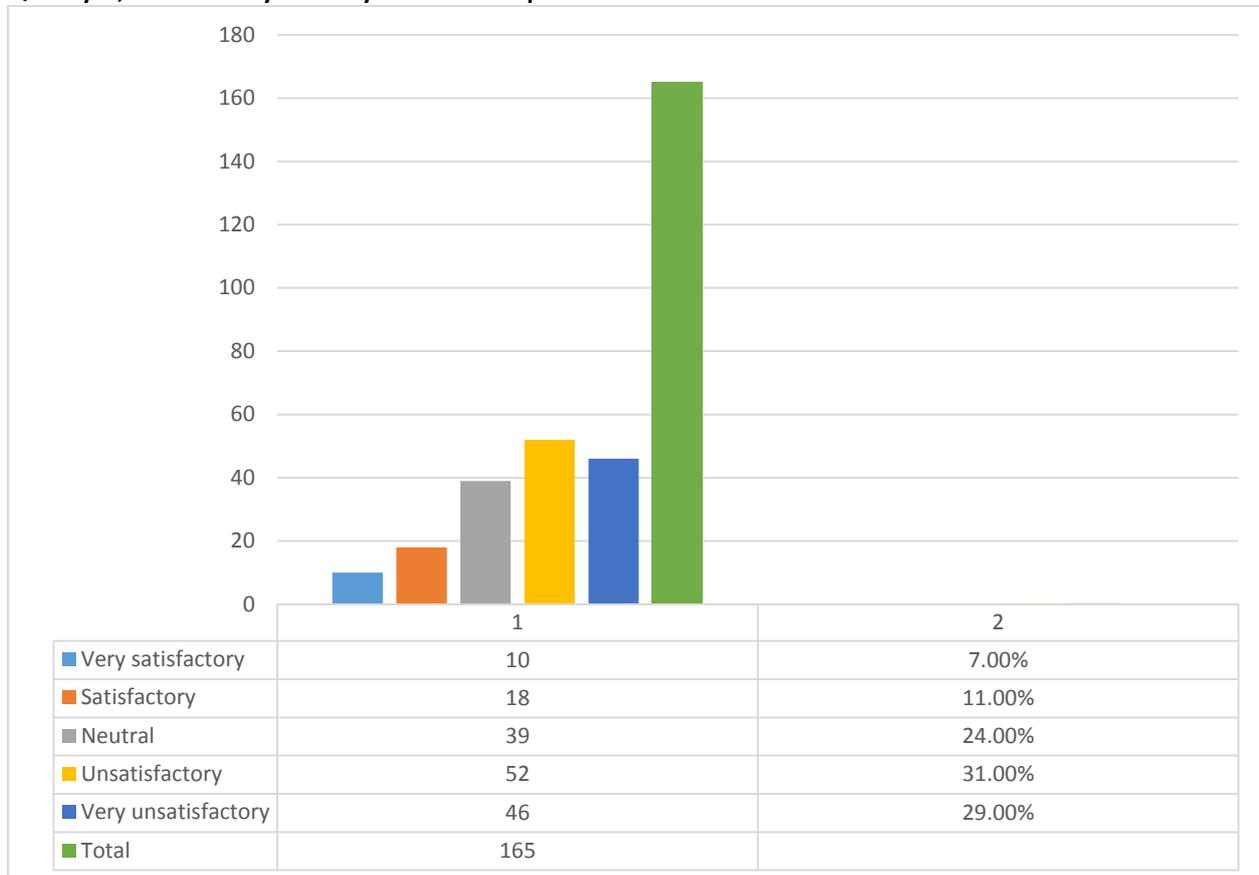
Full narrative is available in appendix D



**Q11 Have you had any contact with the SENAR service?**



**Q12 If yes, how would you rate your overall experience of the SENAR service?**



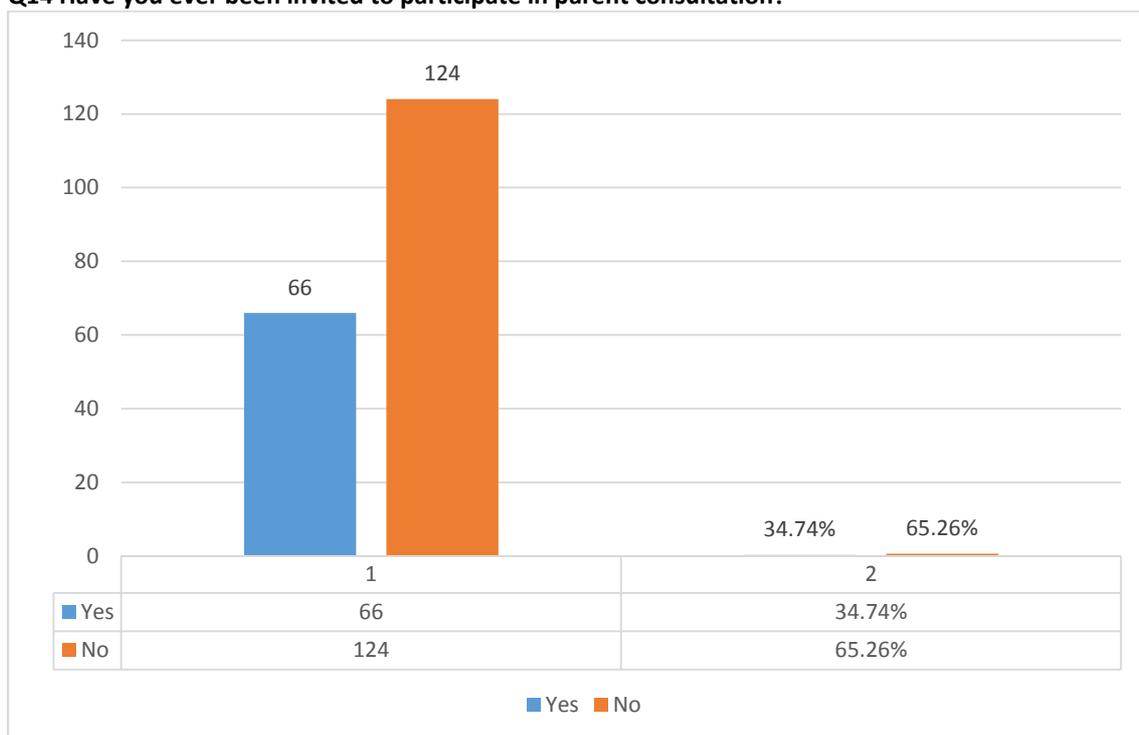
**Q13 if you could have changed one thing in relation to the SENAR service, what would that have been?**

Key words from the narrative

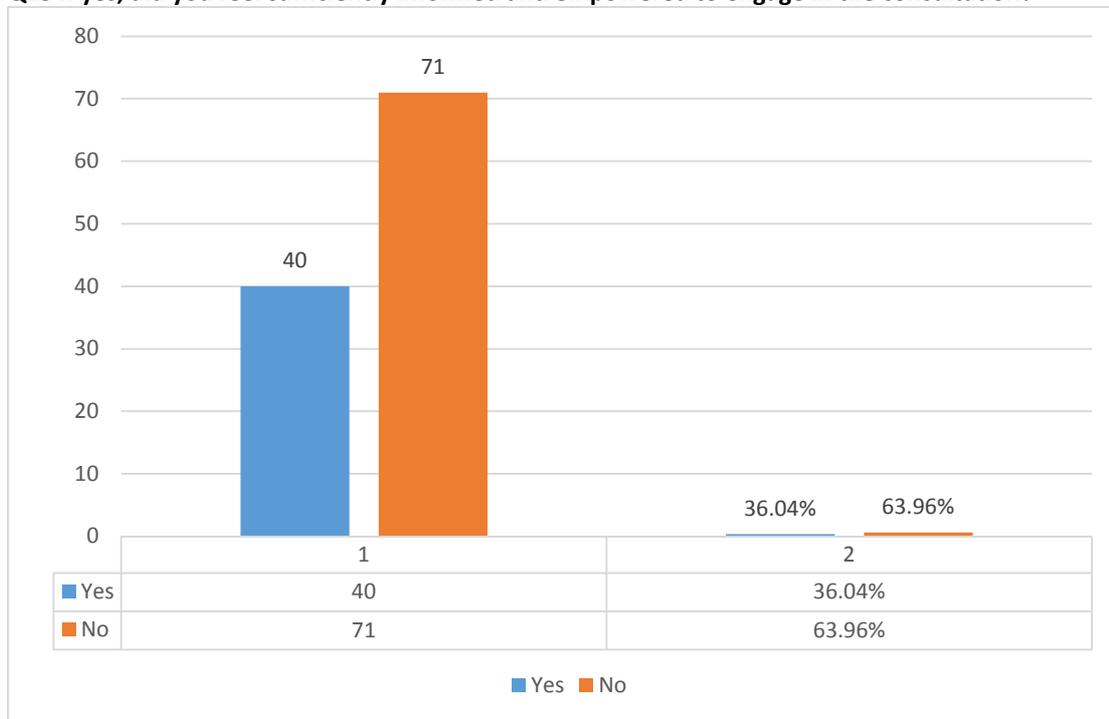
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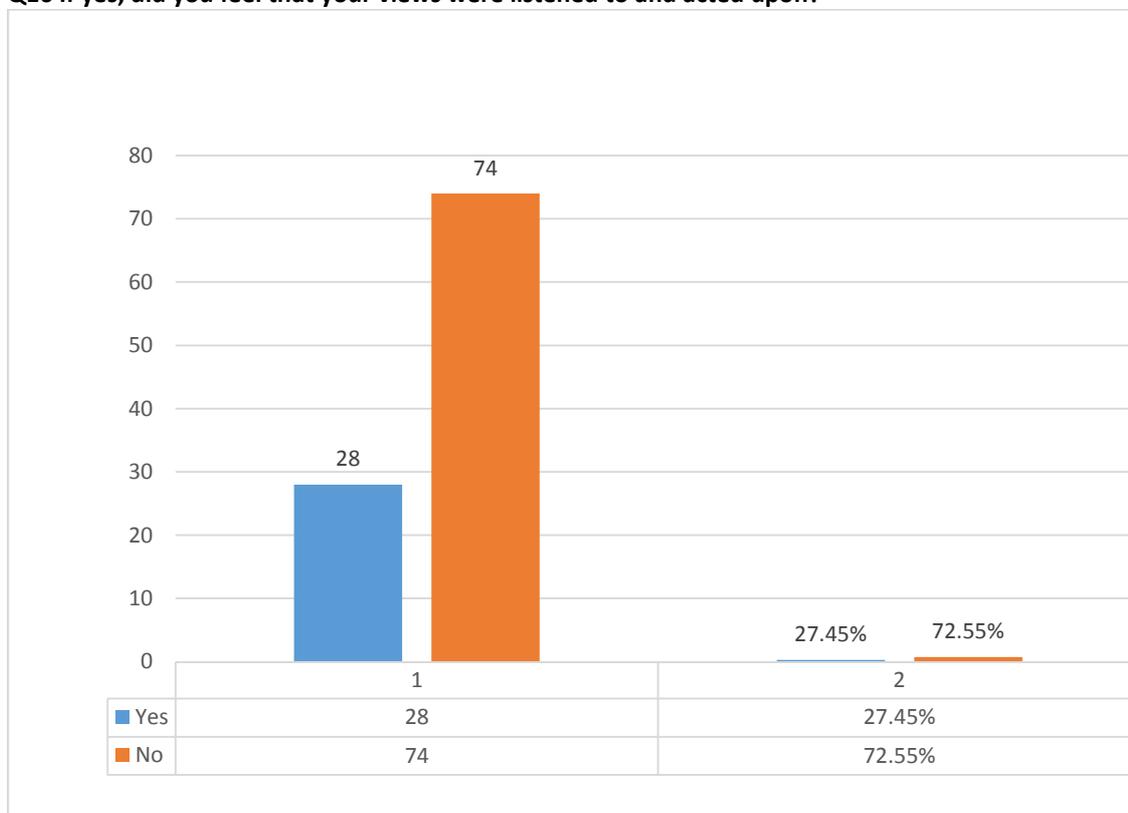
**Q14 Have you ever been invited to participate in parent consultation?**



**Q15 if yes, did you feel sufficiently informed and empowered to engage in the consultation?**

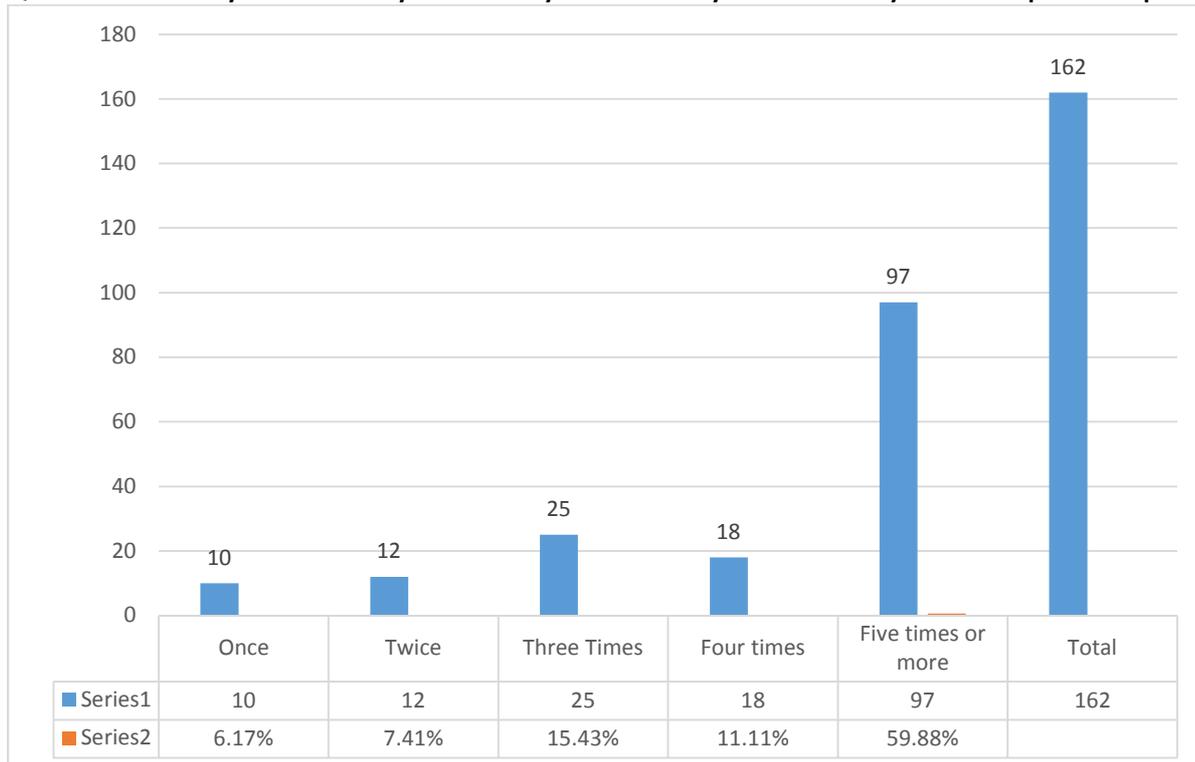


**Q16 If yes, did you feel that your views were listened to and acted upon?**

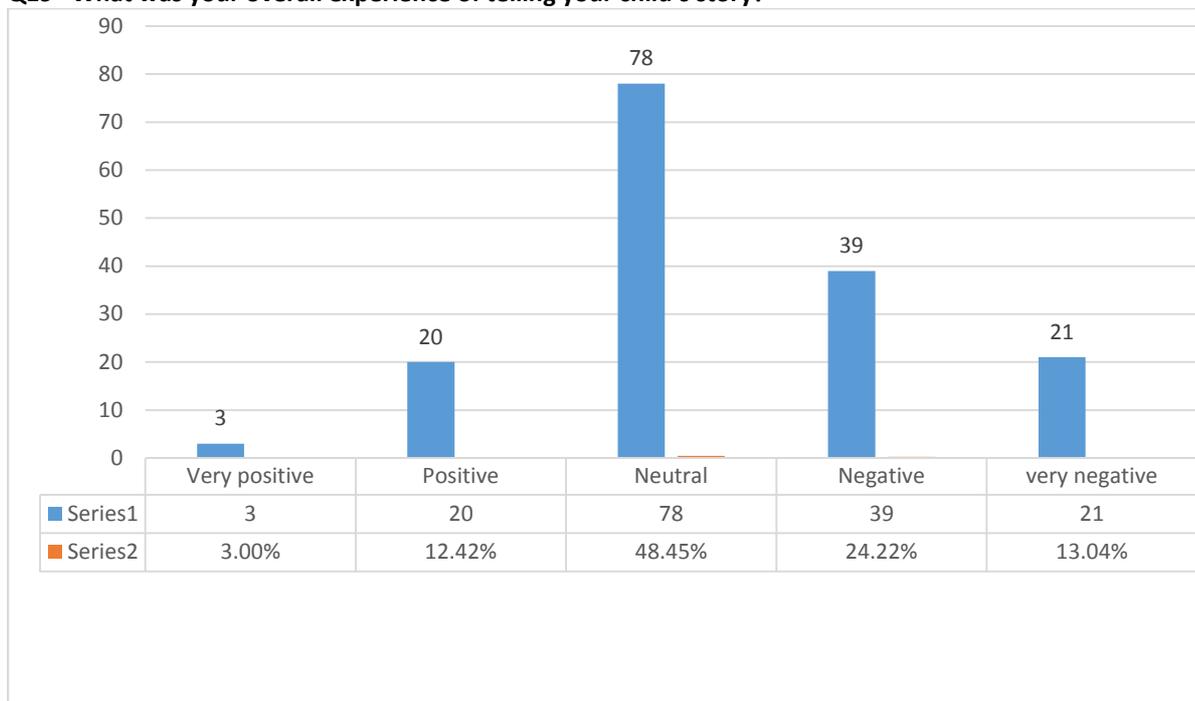




**Q18 In the last two years how many times have you had to tell your child’s story within the partnership?**

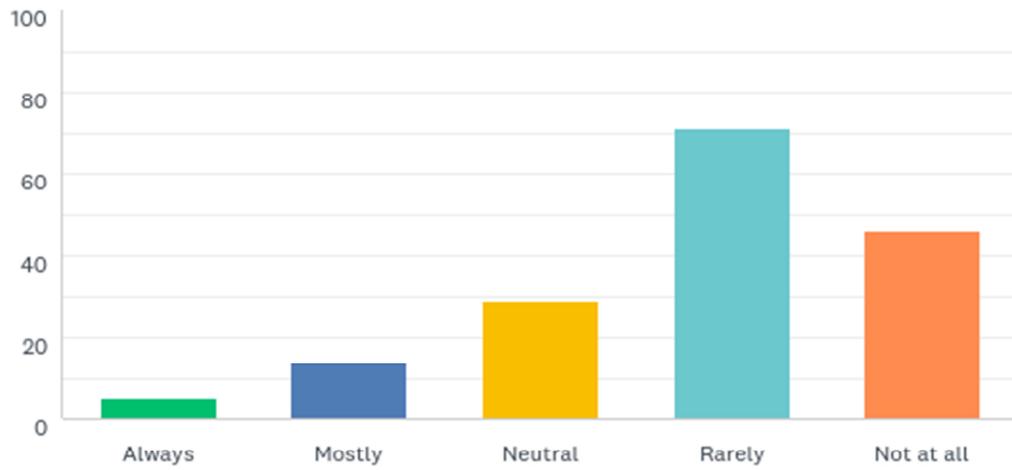


**Q19 What was your overall experience of telling your child’s story?**





**Q21: To what extent do you feel that different parts of the partnership have communicated adequately with each other in relation to your child? For example, do you feel that Health communicated with Education and vice versa?**



ANSWER CHOICES	RESPONSES	
Always (1)	3.07%	5
Mostly (2)	8.59%	14
Neutral (3)	17.79%	29
Rarely (4)	43.56%	71
Not at all (5)	28.22%	46
Total Respondents: 163		

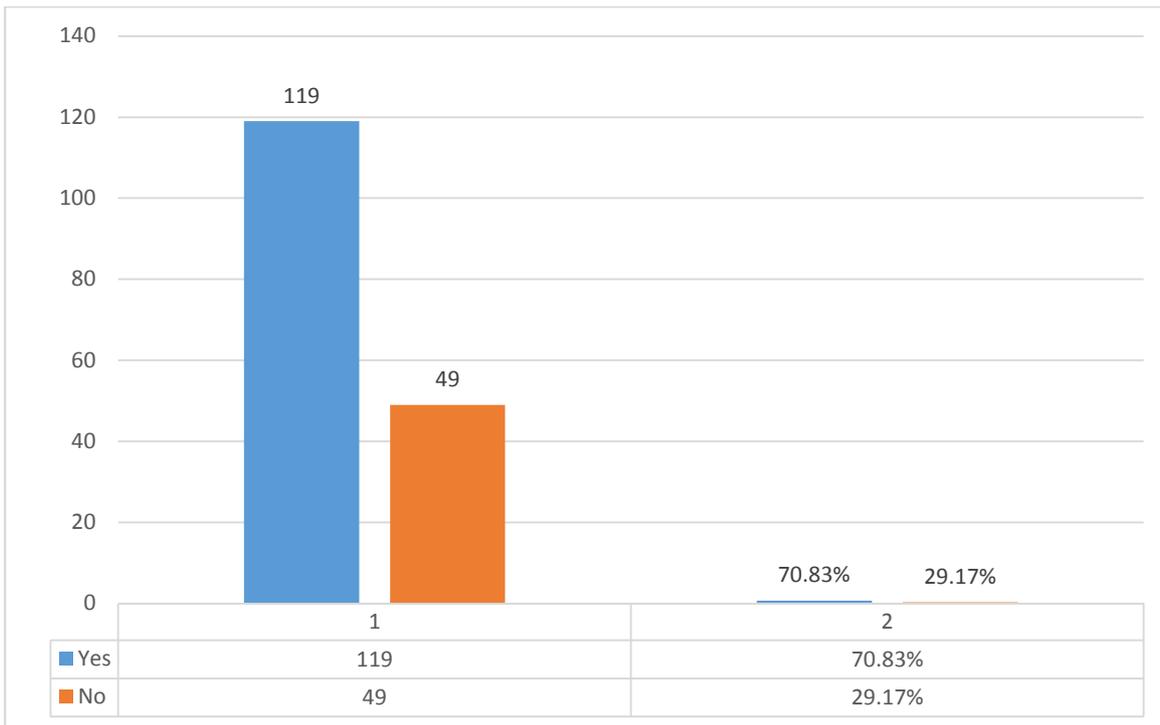
Q22 what, if anything, do you think could be done to improve communications within the service?

Key words from the narrative

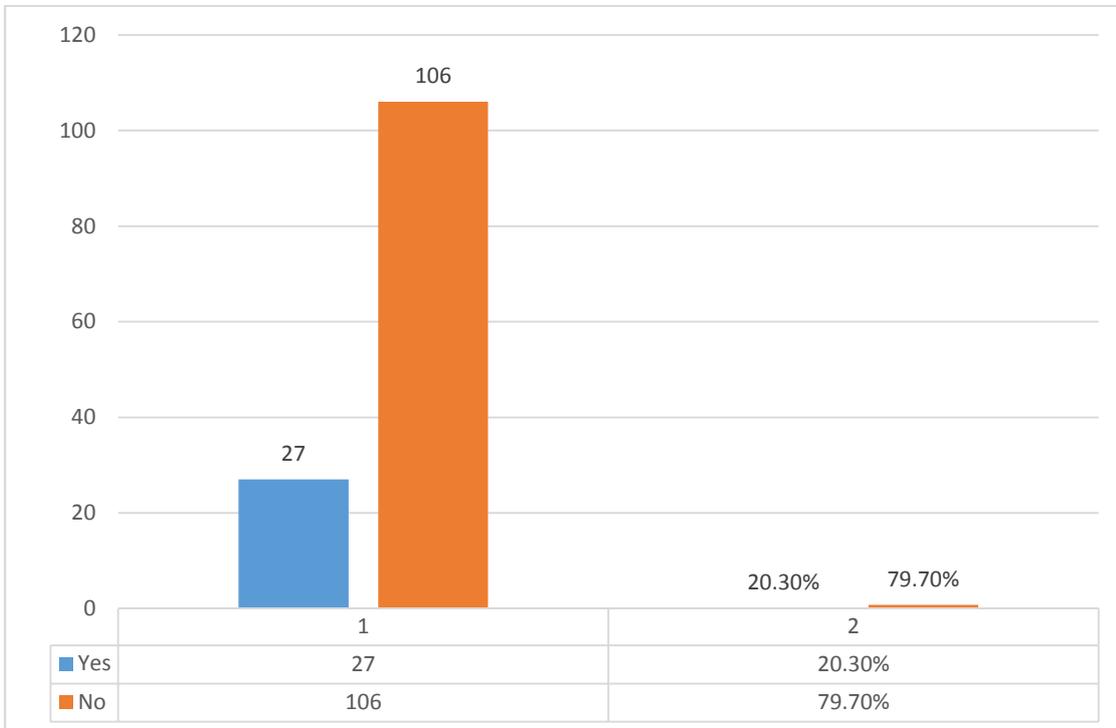
Full narrative is available in appendix H



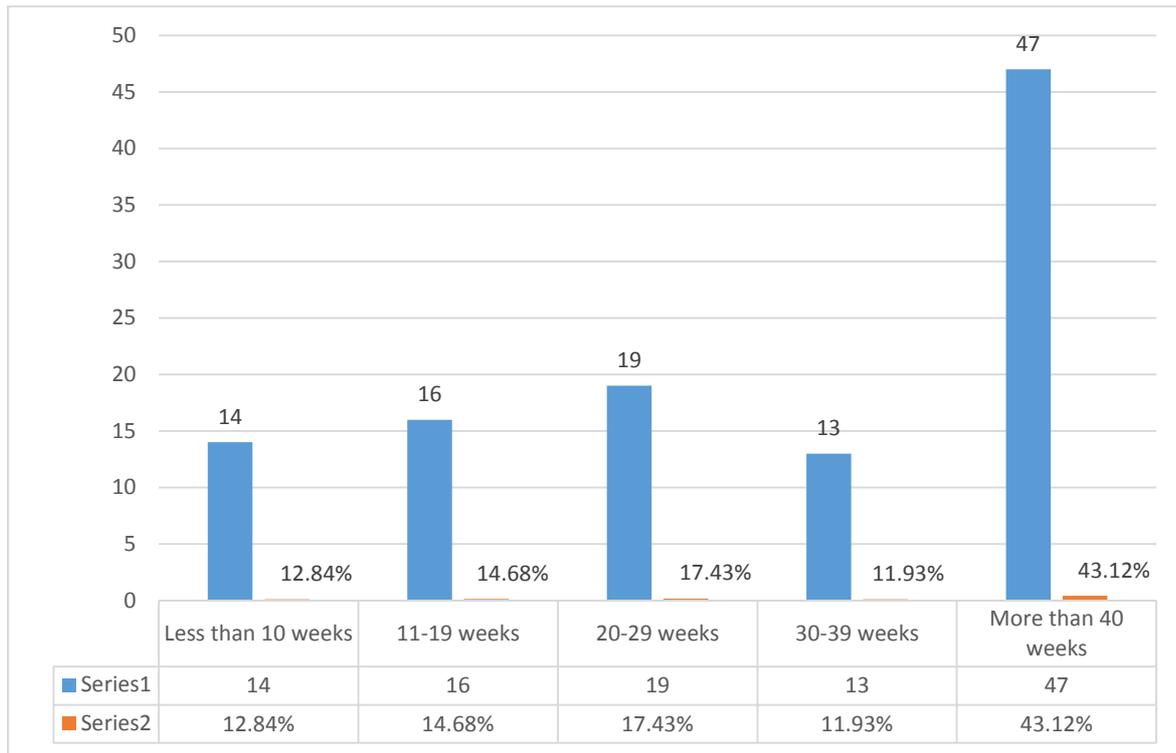
**Q23 Have you ever raised a concern?**



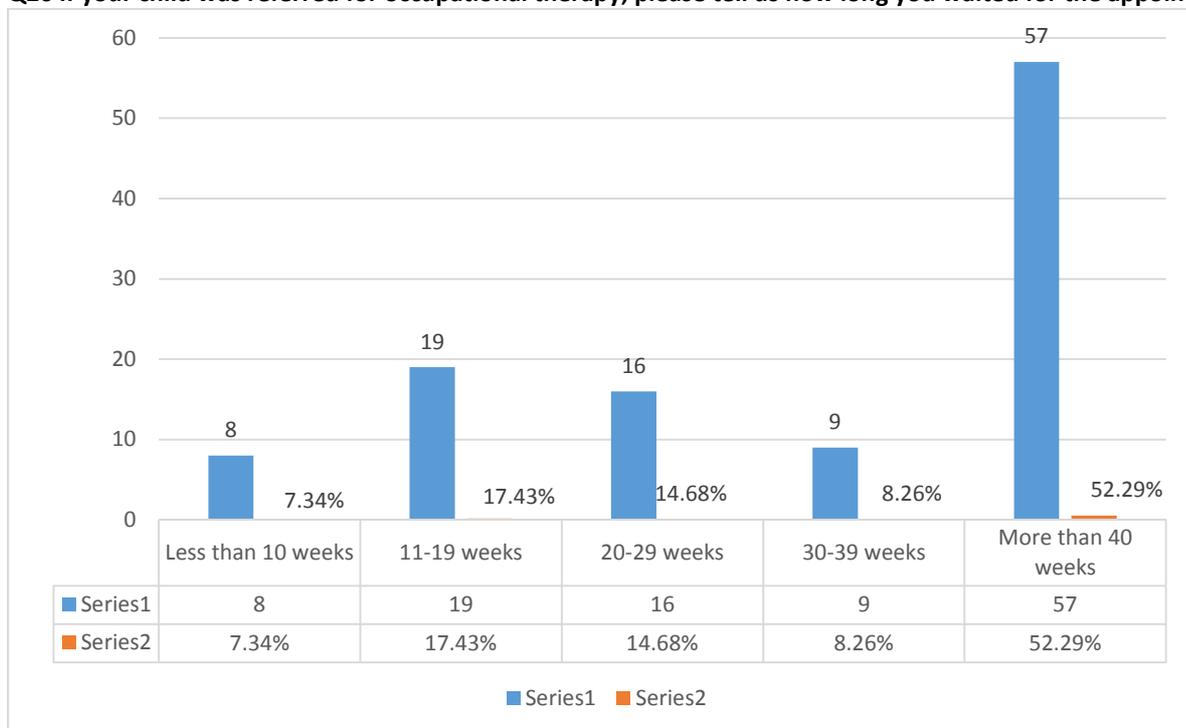
**Q24 If yes, was your concern effectively resolved?**



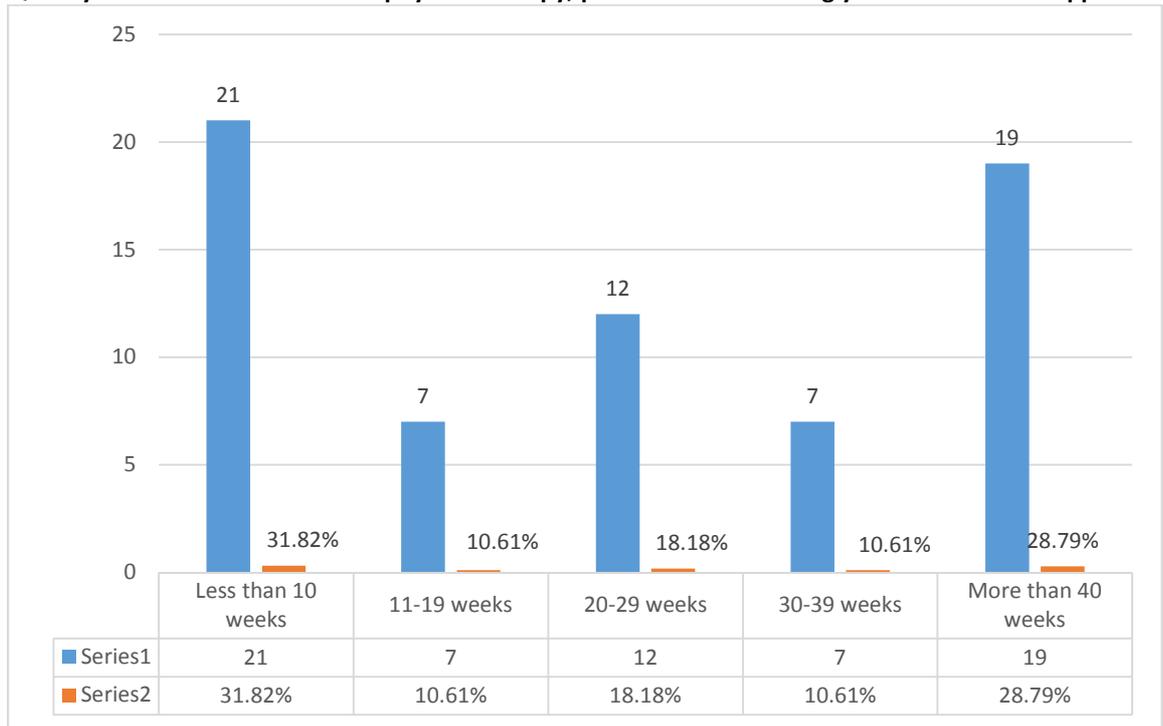
**Q25 If your child was referred for speech and language therapy, please tell us how long you waited for the appointment.**



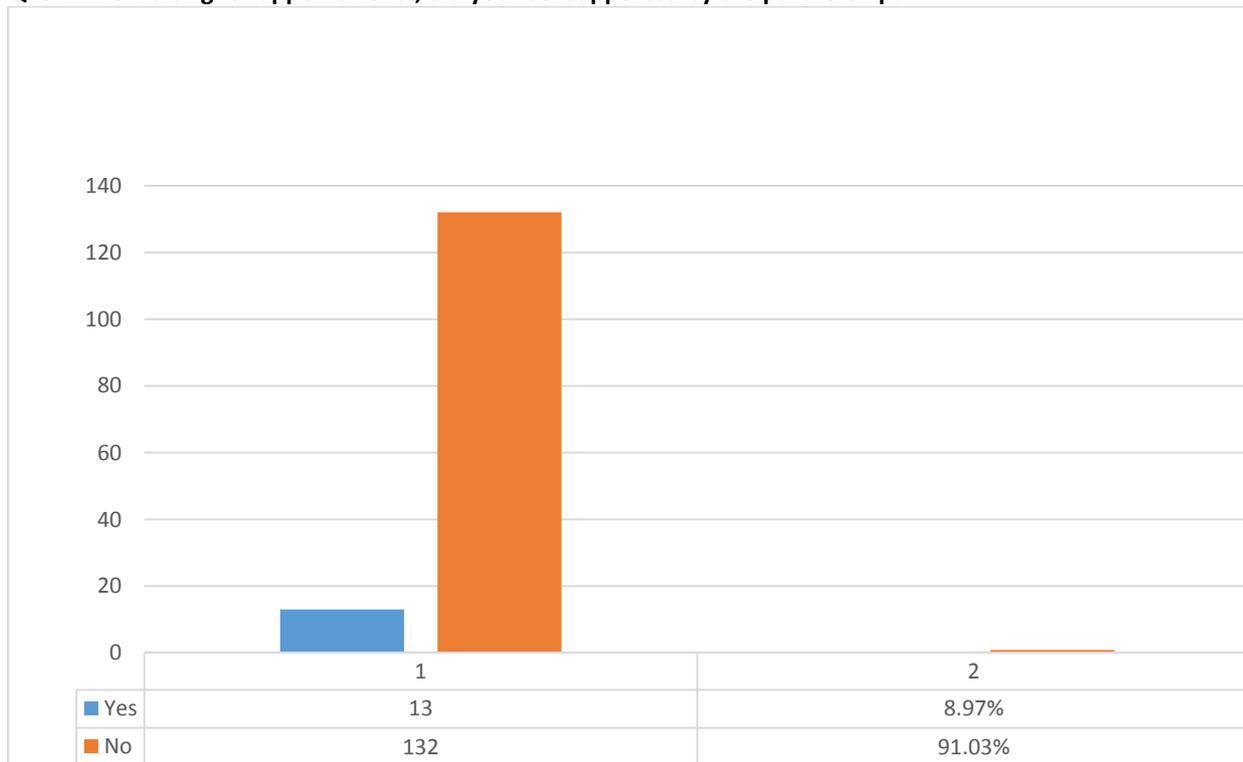
**Q26 If your child was referred for occupational therapy; please tell us how long you waited for the appointment.**



**Q27 If your child was referred for physical therapy; please tell us how long you waited for the appointment.**

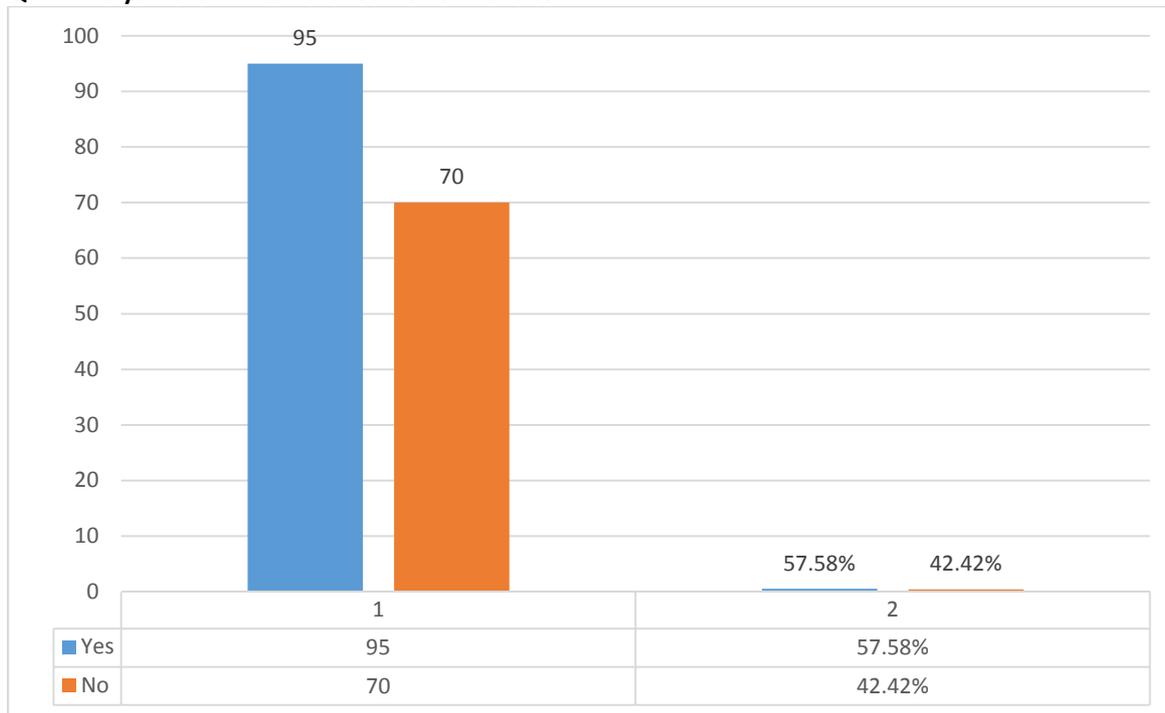


**Q28 While waiting for appointments, did you feel supported by the partnership?**

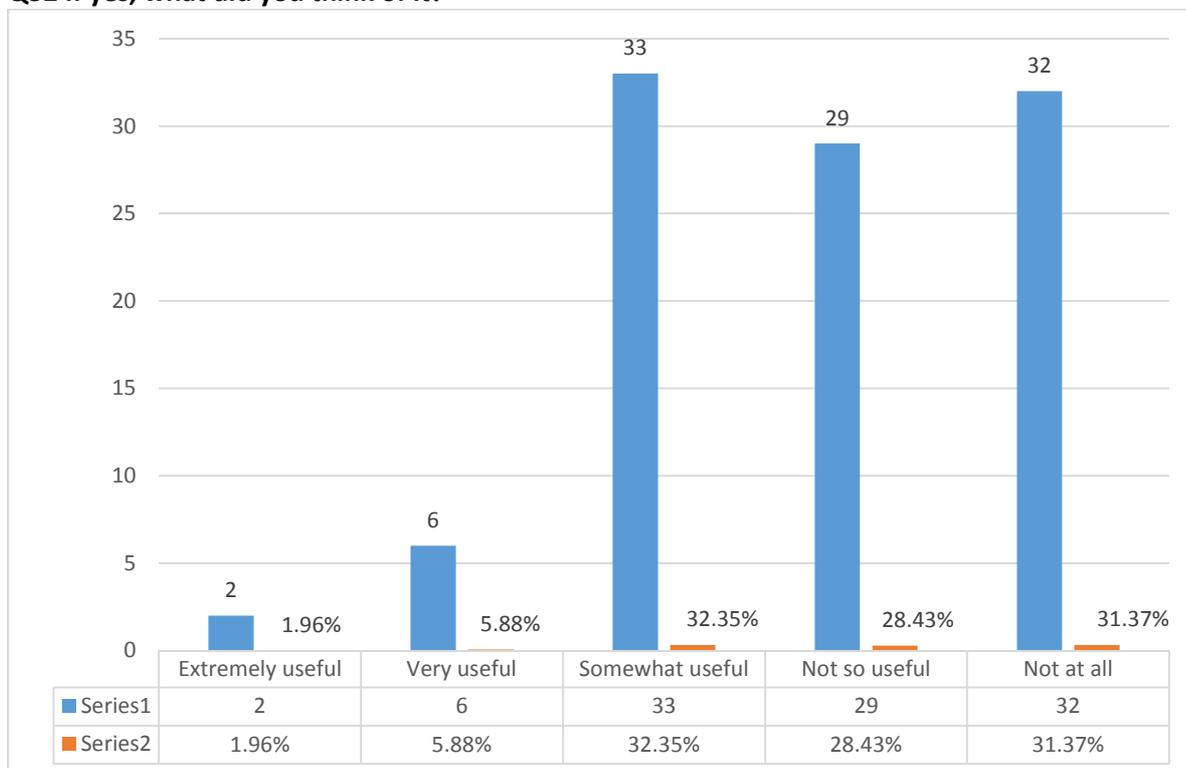




**Q31 Have you ever visited the local offer website?**



**Q32 If yes, what did you think of it?**







## Appendices

The following appendices contain all of the narrative submitted by respondents into the free flow text boxes. The only edit has been to remove any information that could be used to identify individuals.

### Appendix A

Parents were asked if they had applied for an EHC Plan and question 5 asked those that had not to provide reasons.

1. Parents tell me that a lack of insight to their child's brain injury means that they are misunderstood and needs are not understood
2. I am an advocate supporting parents of children with SEND.
3. Lack of BCC support, entirely driven by nursery and parents.
4. She already has an EHCP from another local authority that we transferred to Birmingham City Council mid-September when we moved here. SENAR did not make any adjustments or request any assessments but only reformatted it
5. Unable to receive one due to studying university
6. We are only in the 6 week process at the moment and I think it's very very bad and stressing for us parents with how long we have to wait. My son is now out of education because his school cannot meet his needs
7. The staff at school completing the EHCP are not always clear in how best to complete it.
8. has asd just started school currently seeing how he copes in mainstream before considering the need for a ehc
9. Still waiting on my son getting assistance on this
10. My son had a statement so was assessed for that back in 2014. This has since changed to an EHCP. I was happy with the process when he was being assessed for the statement.
11. An EHCP was never suggested during the time my daughter was at school.
12. For the 4 years she refused until her break down where she was hospitalised she regularly refused school. Not once was it thought she might have issues until we got a family support worker, who suspected autism, when I asked social services for help getting my daughter to school for the second time.
13. Instead, throughout, I was accused of being a bad parent, of not trying, of not caring about my daughter education - she was made to feel guilty and punished and demoralised.
14. Even when, after her hospitalisation and when she was released, no mention was made about an EHCP or mention of SENAR. During her last few months of being under a School an EHCP was filled out but never sent.
15. Over the summer of this year I contacted SENAR and applied for an EHCP for my daughter. She is now 18."
16. My son only got granted ehcp when he went to mainstream school, he should of been granted in nursery, as a result of doing one year in mainstream school his behaviours became extreme putting stress on him, me and his teacher.
17. Paperwork kept on being lost, no agency talked to each other
18. Plan not being carried through
19. They were putting irrelevant information in like the history of domestic violence and social services were involved, years before previously.
20. Was told must have EP report upfront, which is against the code of practice
21. They seem to go out of their way to try not to support the child.
22. "New reports not sought or not included.
23. Content copied and pasted from old statement to new EHCP"
24. "We were advised informally by our son's school's CAT key worker before our son received his diagnosis that he would never reach the thresholds required for an EHC plan. His needs have changed since in the 3+ years since he was first assessed to include health needs/a new serious condition and I don't know if these have been taken into account in how they affect his educational needs by school although school and CAT have been informed of his diagnosis.
25. We do know a number of people who've gone through the EHC plan process in Birmingham in the last 2 years or are in the process currently with children at different schools. All of them have expressed significant concerns with how the process is operating in Birmingham."
26. We have only identified the need for one in the last 4 months and are waiting for our appointment.
27. The process took far longer than the 24 weeks (back in 2015) we were told it would take. I found myself constantly having to contact senar to get updates and to move things along.
28. My son has a diagnosis of ASD. That diagnosis took 18 months – and the whole time that it was happening he was struggling at school. It took 18 months because there is not enough funding available for mental health services and CAHMS. Now we have applied for an EHCP. I have been told that this process will take another 5 months minimum and the application may not be successful. I have been told that often parents have to go to court in order to be successful, fighting the council when their initial requests are automatically turned down. I have also been told that SENAR lost /didn't receive my son's paperwork that was sent to them by his school in September. The school resent it last week. So that's even more delay.
29. The problem is that my family cannot wait any longer for support. My son has had 8 fixed term exclusions, five in a previous school in another local authority, and 3 in the last 8 weeks in Birmingham. He is very close to being permanently excluded. His mainstream school are doing their best, but without an EHCP they cannot give him the support he needs. If he is excluded he will end up at a pupil referral unit – he cannot go to a special school without an EHCP. If he mixes with children involved with crime at a PRU he is very likely to go down that road too as he has little sense of danger or the long term consequences of his actions.
30. Delays in the EHCP system are failing children. It is unacceptable that children have to wait years for a diagnosis or funding because in those years of waiting the children fall apart.
31. Children I know are subject to EHC plans but not my own children.
32. I had to go through an appeal an still yet no special provision for my child even though they have named a special school in my child's EHC plan but he can't go there as they are full

33. Awaiting a EHRC,our preschool has requested one some weeks ago
34. Took well over a year to get processed which meant we missed out on a place at our local sen school
35. Although as admin have received a few calls about these from parents."
36. In my professional role, the ehc plan and provision was not secured the child had NO provision and the child had to be home schooled by the authority
37. Currently awaiting assessment
38. parents have little involvement and the council SEN team lack basic understanding of process, the law, and making individualized plans
39. I think it's just a piece of paper that gets stored away and not acted upon
40. I have experience of requesting EHC plans on behalf of pupils and their parents.
41. very slow process
42. Took over a year to receive back the document at which point it was out of date as we had done the yearly review
43. It takes a long time to go through the process and they lost our paperwork so took even longer
44. Very long process not simple
45. Abysmal Plan
46. My son is Asperger's; he manages quite well in mainstream at the moment. School has never suggested that he should be assessed for and EHCP
47. My child does not have SEND, however the children that I work with do. I'm aware that many have struggled to gain an EHC in transition from a statement in good time and of those who have applied, only one parent has had their child granted an EHC after paying to go private.
48. My son has been failed by the system. I was emphatically informed that he could not be reassessed at the time his needs increased when he was 12 because ' it's never done' he is now 17 and desperately needs an ehcp as his list of reasonable adjustments is longer than many young people have on their ehcp.
49. Apparently didn't qualify for one
50. Complete ignorance on behalf of the school. Senco had never heard of ASD, child is obviously not achieving any age related targets, yet this appears to be completely ignored, and requests for further assessment have been ignored.
51. Never been discussed with us as parents of an autistic child
52. My daughter is just starting the process. It is very complicated and lengthy. It has taken from reception until year 4 to apply even though she's never met one of her individual targets.
53. I have twin sons with Autism both diagnosed by Child Development Doctor at a Hospital however the twin has a EHC and his needs aren't being met by the mainstream school I have requested a change of school to a special needs school as I have evidence his getting worse and not progressing still senar have refused me and stated his needs can be met at a mainstream school so I am appealing this with the help of a solicitor
54. My daughter as got co and autism and other problems
55. We have been trying to get one now for 2years
56. Senar not interested in what's best for young person, only what saves bcc money.
57. Refused to assess , mediation, child out of school for 10months
58. Our school refused to put our child forward for assessment
59. As a Deputy Headteacher and SENCo in a Birmingham school I regularly support parents at annual reviews and on occasions I have supported parents to apply for an EHC for their child. Sadly I am no reviewing a review of a review of a review having received no amended EHC for 6 out of 8 children in my setting who have an EHC. Of the EHC that have been amended both have had incorrect information. Contacting SENAR is problematic and I often have no reply to emails that I send in relation to children on our roll. It is only when parents involve SENDIASS that SENAR will engage with parents and school.
60. My school refused to put one in for my child. Saying that it is too much paper work and that it will just get refused
61. School won't do ehcp and have tried to put me off by saying well ur daughter wont get is as she only has autism and is not physically disable
62. Too long, constantly had to chase up, no understanding of questions
63. Was told my son is academically able. With no thought about his mental health, social and emotional needs
64. We had no end of problems with SENAR. Our principal officer failed to return any of our calls and everyone else we spoke to was unable to action anything. Eventually we resorted to contacting our MP who wrote to the Head of Children's services!
65. Child suffered developmental trauma and has inhibited ability to access learning due to high level of anxiety
66. lack of needs of whole child needs social and health and other key people involved out of school
67. Too much copy and paste
68. Have been told it is very unlikely for people to get an EHCP.
69. Always being told she doesn't qualify for the assessment
70. Requested an assessment as advised by children's services in April it's now Oct and not had a response
71. My son is diagnosed with autism and has just started reception. An EHCP hasn't been suggested yet and we are unsure whether to proceed.
72. SENAR officer was incompetent, uncommunicative and delayed the process to a damaging level.
73. Parental application declined to assess at week 6 deadline because school had been given an extension. Then declined at appeal as school needed time to apply strategies they'd been told months before
74. Too young yet
75. Took longer than legal timelines, refused to assess so had to appeal. As soon as they did assessments it went straight through so there was OBVIOUSLY reason to assess, can't get hold of main case worker ever!
76. It was turned down by panel, since I've gone to tribunal and won. My daughter has complex needs and the LA say she didn't meet the criteria for assessment. I told them things were getting worse and my daughter is now only in school for mornings.
77. My child's school does not support the need for a plan despite my child's struggles. I had a teacher comment however that the school would receive money if he had one.
78. Because travel is kept separate you can have one without the other
79. Told by schools it's a long process and probably not necessary.
80. The length of the assessment was far beyond the legal guidelines. I could not contact senar when I needed to and neither could the professionals I was working with. The school was no help at all, in fact a hindrance. LA did not turn up to mediation. I had to get solicitor involved after 12 months and only then things started slowly moving. All the while my son was not in education for 20 months at age 10/11.
81. No P.O. present, all educational not care needs, illegal wording, senco way not took parents views, time scales not adhered to
82. It dreamed as able to get the support by teacher
83. Not a parent

## Appendix B

### Q6 - What were your reasons for requesting an EHC Plan?

- 1 To support a child or young person's education, health and care following an acquired brain injury
- 2 Nursery found concerning issues with both of our sons, requested EP to assess and hence recommended EHCP route to gain access to special school & resource base school.
- 3 My son has Down's syndrome and autism and severe learning difficulties
- 4 My child has special needs that requires provision to be in place to meet those needs that is over and above the school's resources. This included additional therapy and staffing. My child has not coped in school since Recepti
- 5 My son has Aspergers and Dyspraxia
- 6 Diagnosis of asd and requiring support at school.
- 7 I needed further support at college
- 8 My son has special needs and cannot cope in mainstream school so now he has been excluded
- 9 Child has Autism and epilepsy.
- 10 Not responding to name, overall developmental delays, over all autistic traits.
- 11 Autism non-verbal still in nappies. Needed to go to a special school
- 12 Child has autism and severe communication disorder
- 13 Son has autism, ADHD, and is 3 years behind in his learning
- 14 My son has autism.
- 15 My reasons for requesting a statement were that my son was (and still is) significantly behind his peers. He needs a lot of extra support to be able to access the curriculum and learn.
- 16 Support needed in school to meet my son's needs.
- 17 Child struggling in school
- 18 My daughter is autistic, she has problems focusing in the class room due to the group noise, the pressure of the people around her, bleeding from her eyes, ears, nose and hairline, sensory overload, anxiety etc etc. She needs to be able to leave to avoid melt downs, she needs written confirmation of verbal instructions.
- 19 Since she's missed a good 2 years' worth of education (at least) I'd love for her to have access until she's 25 so she can be all she can be."
- 20 Through assessments of our son it became clear he would struggle immensely going into mainstream school and he needed extra provisions and support put in place for his educational needs.
- 21 Son unable to access lessons as couldn't stay in classroom due to high numbers.
- 22 He was diagnosed autism at age 2 his behaviours were extreme, poor concentration, learning delay of 2.5 years, unable to sit for longer than 30 seconds
- 23 Complex health needs, developmental delay, deafness
- 24 my son is autistic
- 25 Regular exclusion
- 26 My son was diagnosed on the ASD AND SENSORY ISSUES
- 27 To get my son the right support and to be in the right school
- 28 Salt delay
- 29 Child really delayed, being internally excluded, hating going to school, deteriorating mental health
- 30 My son attends a special school. Mainstream couldn't meet his needs.
- 31 Had a statement of special educational needs and needed to transfer to EHCP when going up to secondary school. (Statemented originally for autism and was at risk of exclusion - was excluded twice).
- 32 We think our daughter has PDA. She was in mainstream school until in yr 11 the problems came to the fore.
- 33 Child has disabilities
- 34 Child has been excluded on numerous times and was on the verge of permanent exclusion (although this would have been illegal). My child needed specialist provision as school refused to try and accommodate
- 35 Child diagnosed with severe dyslexia & dysgraphia & was close to age 16
- 36 Complex needs
- 37 My son needs support with his ASD.
- 38 My son is Diagnosed with ASD and require extra support, mainly 1-2-1
- 39 Son is PMLD. Had statement since age of 2.5.
- 40 The diagnosis of my child and all the difficulties that my child was showing were much greater than a normal child his age
- 41 Autistic child
- 42 My son has autism and has a learning disability
- 43 Lack of overall support, lack of recognition of his needs and was receiving a high level of exclusions with no action plan of practical support or suitable interventions.
- 44 The child's needs required it
- 45 Our child needs additional support at preschool and then school
- 46 Child has disabilities since birth
- 47 Complex need and school struggling
- 48 not applicable
- 49 My disability
- 50 Unable to manage mainstream setting
- 51 My son has educational needs
- 52 Child with additional needs whom requires SEN.
- 53 Childs needs are not being met in mainstream school.
- 54 In my professional role I worked with other professionals to try and secure specialised provision ready for school
- 55 Complex needs need to be taken into account.
- 56 I believe my son needs one I order for his school to take his autism seriously
- 57 my child has complex medical, and learning difficulties
- 58 Significant learning, social and emotional needs. Multiple diagnoses and LD
- 59 I didn't request it. My child had a statement of SEN mad was transferred to an EHCP
- 60 My children were born with a condition so have always been in the system.
- 61 Health, MLD
- 62 My daughter is autistic and needs extra support at school
- 63 My sons statement transferred to EHC
- 64 Followed in from educational statement
- 65 It was my sons nursery that he attended, that requested an assessment be done, as they noticed signs earlier than what I did, and brought it to my attention. As a first time parent I had no idea my son wasn't reaching his milestones as and when he really should have been.
- 66 Children making progress, high levels of need and support in school
- 67 My child has significant needs
- 68 Learning difficulties
- 69 Non-verbal child
- 70 One child diagnosed with global developmental delay
- 71 Second child diagnosed with autism
- 72 Child is in special school
- 73 My child as Asd and Adhd
- 74 It was a transfer from his statement
- 75 He had a statement and was automatically transferred to EHCP when he was reviewed at school

76	My child has downs syndrome	114	Significant learning difficulties, SEMH needs
77	Disabled daughter	115	Daughter has a rare neuromuscular disease
78	Diagnosis and learning difficulties and other issues	116	Daughter has been diagnosed with autism and she self-harms and has severe anxiety and she need support at school and outside school
79	Child with SEND	117	Transition from Statement
80	Our 11 yr old ADHD ASD dyspraxia was failed by school system for three years and about to sit sats and transition to secondary school	118	Social and emotional and mental health
81	Within my workplace, initially children are assessed by the school SENCO, who then informs an appropriate external agency that another assessment is needed, from this, including parental views, an EHC is requested if necessary. This is generally due to behaviour within mainstream settings, or an inability to access the curriculum as well as their peers due to their specific need.	119	Our son was diagnosed with ASD, hypermobility and global development delay and therefore would not have coped at a mainstream school.
82	It was a yearly review at school	120	My son is Autistic /ADHD and has learning disabilities. He wouldn't be able to cope in mainstream education setting
83	See 5.	121	To properly assess need and put strategies in place as educators not expert in the effects of early years trauma
84	He has diagnosis of Asperger's. He has developed a range of social and educational needs that were not there when diagnosed at age 8."	122	Daughter had ASC diagnosis & was not receiving adequate support in school. Ended up out of school as she was unable to attend due to the enormous stress she was under
85	Not applicable	123	My son's levels of attainment are significantly behind his peers at school. He also has a diagnosis of autism.
86	Pupil required specialist provision	124	parent requested
87	Daughter has cerebral palsy	125	It was set-in motion from Senco when my daughter attended nursery from the age of 2
88	To support my son with his education in a main stream school. He was diagnosed with Cerebral Palsy and a rare genetic condition called Joubert Syndrome.	126	Additional needs
89	Adhd and asd	127	Transfer from statement
90	My child has global developmental delays, Down syndrome	128	It was required for my daughter in special school
91	My daughter has high anxiety has Asperger's these have great effect on her everyday life and education	129	Autism and ADHD
92	Child came in to care clearly exhibiting many traits of ASD, and at 6yrs old unable to read, write, play, engage with others or even stay clean/dry throughout the day. This is apparently normal to the children attending this Birmingham school, who were rated by Ofsted as inadequate in 2014, with no obvious improvement sinc	130	Not coping at all in mainstream school very anxious not going to school
93	Health needs	131	My son was diagnosed with autism, learning disabilities and development delay
94	Child believed to have autism	132	Autism, high anxiety, sensory processing disorder.
95	Never been offered one, never been discussed	133	Child in need of support and self-harming in school
96	My child has abnormality with his behave.	134	My son was diagnosed as autistic at 3.5 years old
97	Our son has physical & educational/behavioural disabilities (cerebral palsy, ADHD, autism, dyslexia, sensory processing disorder) & is a wheelchair user. He has had a statement/EHC plan since starting school to accommodate and bring together the different elements of his support, in a mainstream setting.	135	My son has ASD and PDA and his needs were not being met in his mainstream primary school. He was often excluded as the staff at the school could not see the reason for his behaviour was his extreme anxiety around demands and treated him as being 'naughty'. The majority of teachers at the school (including his class teacher) had no concept of invisible disability and when we requested adjustments we were told many times that to make an adjustment for our son 'would not be fair on the other children'
98	My daughter has learning difficulty and is very behind with most of the curriculum, especially speech, language and maths	136	Transfer from statement
99	It was the school who requested one	137	Asperger's, Sensory Processing Disorder, Anxiety, school refusal.
100	To see if she's entitled to it	138	Asd adhd struggling in mainstream
101	Adhd / learning difficulties / high anxiety	139	As my grandson struggling in mainstream they were able to meet his needs
102	Our child has high anxiety and stress and cannot deal with loud and crowded places	140	My son has PMLD and complex physical and medical needs.
103	Disabled	141	Pda anxiety sensory indicting on concentration to study
104	Autism, mental health and missed education.	142	No reasonable adjustments
105	Child not coping in mainstream, behind in education.	143	My daughter was born extremely premature and spent the first months of her life in the NICU. She came home, on oxygen with lots of issues around feeding, sleeping etc. She had delays in standing, walking and was non-verbal until she was pre-school. An EHCP was requested as she approached school age it was apparent she would need additional support in all aspects of her day-to-day. A diagnosis of ASD was given and the EHCP requested after an initial assessment by an EP.
106	Diagnosis of Autism and Learning Disabilities and increasing behaviour that challenges.	144	N/a
107	Low achievement, well below average. Anxiety and proprioception difficulties	145	Looked after child with global development delay diagnosis and attachment difficulties
108	He was unable to access the appropriate support without it	146	Multiple needs, hearing impaired, hemiplegia, non-verbal, learning delay.
109	child/young person transferred from a statement to an ehcp.	147	My son converted from statement to EHCP
110	The needs of the children on roll		
111	Need based on condition.		
112	My son is struggling with school and is being punished in lessons for this		
113	Educational psychology did due to severe global developmental delay		

- 148 Child has additional needs and requests 1.2.1 support.
- 149 My daughter has ASD and ADHD and requires additional support in school. Wasn't making progress or having all her needs identified
- 150 Already had a statement in place
- 151 My son has complexed needs
- 152 My daughter's school we're not meeting her needs.
- 153 Not coping at mainstream school. Having a diagnosis of autism and adhd after school refusal and having a mental breakdown he was given an EHCP
- 154 My child struggles daily, he is medicated at the schools request, he requires 1:1 In order to keep him on task and to provide support.
- 155 My son has severe cerebral palsy, sensorineural hearing loss, asthma, dysphagia, learning difficulties,(cognitive age of 7), non-verbal, wheelchair dependent and dependent on me for all his basic needs,(feeding, bathing, toileting, etc..)
- 156 Transfer from statement
- 157 Autism and ADHD
- 158 My son struggles with social situations and his behaviour and emotional state has suffered.... all due to his autism diagnosis
- 159 Daughter has multiple disabilities and learning delay
- 160 Daughter has ASD and Learning disability
- 161 Autism
- 162 School requested to get my eldest support in school he needs
- 163 "Learning delay, asd, spd, fine motor skills delay well below his peers.
- 164 Anxiety disorder asd pda not receiving full time education in a setting and environment suitable to age and disability "
- 165 To get my son the support he needs within school
- 166 Autism spectrum disorder, Dyspraxia, school refusal, anxiety, sensory processing disorder, diagnosis's.
- 167 Son not making progress at school, school unable to cope with challenging behaviour, school not having time or resources to deal with my son and educate him in an environment suitable for him. Leading to my son refusing school and escalated challenging behaviour due to anxiety. "
- 168 My son is not coping in mainstream he ends up on reduced time table for a hour a day he has said in his own words he is sick of being bullied for being different and wants to be with others the same as him.
- 169 Needs were not being met for many years
- 170 SEN , disability needs
- 171 My son received a double diagnosis of ASC and ADHD when he was 5 yrs old. He has additional educational and health needs which have not been addressed in mainstream settings. Following numerous difficulties in his first mainstream primary, I did a parental request for a statement. This supported his need to access more specialist provision. The statement was transferred to a ech plan last year.
- 172 Child/young person has cerebral palsy, ASD, anxiety and depression. She needed support to be able to access her education.
- 173 To ensure my so. Had the best provision and support
- 174 Child has autism and not managing in mainstream classroom

## Appendix C

### Q9 – Parents were asked if they experienced any challenges with the plan and if yes, please give brief details

- Lack of insight and awareness to the difficulties in respect of health care and education following an acquired brain injury
- Unlawful decisions re refuse to assess, refuse to issue and contents of EHCPs
- Yes with getting the correct provision named on the plan
- Things I wanted the plan were often met with opposition
- A resistance to deliver the requirements of the SEND Code of Practice. I was at breaking point and my child self-harming due to the failings within the system.
- The LA refused to assess firstly
- Waiting longer then the legal timelines for draft and final and one occasion where the annual review wasn't processed at all!
- Wasn't eligible due to level of education I was in. eg. uni
- Setting the long and short term targets. It's easy if the school have up-dated accurate records on the child.
- Still in process of getting a plan in place
- Understand my impact on my child future
- Unable to name special needs school in first plan, having to request an early plan to ensure school place is awarded in time
- Support from the school
- We were delayed waiting for an appointment with the CDC for assessment for a diagnosis.
- It's poor, all SEN are not on there, amendments I've submitted haven't been put in, it's not specific or quantifiable and the school I want isn't named.
- Could not get quantification of support by Local Authority.
- Many items suggested my parents were rejected. Especially section d.
- 1st draft missed out loads of information was only when a meeting was called that plan was considerably better
- BCC not keeping to time limits, inadequate funding in schools to implement recommendations.
- no one at the school would admit my son was autistic and did not want to do a ehc plan
- staff in school / nursery not equipped to make assessment and provide appropriate evidence for plan
- The process of 18 months was a very hectic time for parents like us but I have to agree my sons educational psychologist and the senco practitioner at nursery was so efficient and so professional towards their work for my child. The time and effort they had put in was marvellous I can never thank them enough. We wouldn't have been where we are today without their help. It was a slow process and I understand how much information is required but to start with the whole plan was very daunting for us but it was a success at the end
- I didn't want the history of DV or social services mentioned in it. I was ignored.
- Finding information, making sure information got through,
- "Initial statement - parental request, school weren't supportive. By the time SSEN was finalised my son had become a safeguarding ""problem"" and his school said they could no longer meet his needs. LA issued final SSEN with no placement named - section left blank! Eventually placed in special provision 9 months later.
- Move from SSEN to EHCP **did not follow legal requirements**. No involvement from SENAR - all done by school. Mostly copied and pasted despite parental requests for updated reports. All ""woolly"" - no specifics in provision."
- As it was me to school staff, they initially didn't have a clue what to put into it. Ongoing up to secondary school, an ill equipped Senco with very little experience. SEN chose to disregard many aspects of the plan.

- Unfortunately this lead to multiple behavioural sanctions and massive breaches of the disability discrimination act (both direct and indirect).
28. Getting a tac meeting. Also head teacher was initially against it until we pointed out it was our child's right to an education
  29. The ehcp was badly written, OT assessment was missed even though it was advised in 2 professional reports OT assessment was needed
  30. Long delays.
  31. They refused to assess my child had to go through an appeal which took a year and still is not right
  32. Son had a SEN and was transferred to an EHCP with school assistance. All health professionals send their reports to be included in the plan. SENAR took out a lot of the necessary information and tried to simplify the plan, therefore making it less effective. This undermines all the hard work put in by the professional, the school and parents.
  33. The lack of connection between all agencies to inform all areas of the plan and quality of reports to inform how the actions were to be delivered
  34. Gaining parents involvement and engagement
  35. Waiting for a response, the pre-school has no experience of doing one before
  36. The time taken to complete the process
  37. Staff are unsure what details need to be completed and have had them returned.
  38. Parents are unsure of process.
  39. Not all administrative staff are aware of the EHC application or process so unable to support parents and respond to their queries"
  40. Funding my plan funding dispute
  41. Time scales
  42. No support from SEND, especially transferring from original statement, more of a learn as you completed.
  43. The ehc assessment wasn't carried out properly. Only an EP saw the child and the family didn't see her report before it was submitted.
  44. School Provision not secured i worked in an early years sector.
  45. If it wasn't for me SENAR would of forgot this child completely
  46. I ended up coordinating a lot and having to get further advice and support where official investigation was made "
  47. The LA refused to listen to me and got all the Needs sec B and provision sec F all wrong. Several meetings failed to address my concerns leading to me appealing sec B and F. Our appeal was upheld. Further problems occurred later with PB.
  48. Too many to write about
  49. "An attempt to remove certain provision altogether.
  50. A number of diagnoses recognised on his statement removed from his EHCP
  51. Changing specific, quantifiable, agreed provision for vague suggestions
  52. The biggest issue I have, however, is that the LEA is no longer duty bound to provide a suitable education. Every part of the EHCP includes the phrase 'where possible' or 'dependent on resources' or 'where compatible with the efficient use of LEA budgets
  53. None
  54. Unsupportive primary school SENCO
  55. We did not receive a full assessment required by SEN Code of Practice and had to complain to Head of SENAR.
  56. SENAR do not always meet deadlines and do not attend meetings. A lot of the work is left on SENCO's.
  57. It is very difficult to get information and representation from health and social care professionals.
  58. took 3 years
  59. Very complicated, took a long time to do
  60. Is very general felt like waste of time
  61. The money doesn't seem to be spent on the child
  62. Expectations and reality didn't meet, a lot more budget issues and challenges
  63. School not backing due to lack of experience
  64. Awful service
  65. Senators had to go to tribunal as school unwilling to help with extra costs and LA were a joke
  66. I am currently trying to complete an application myself as a parent, but am aware that so many key words and phrases are needed for the procedure to see him as needing an ehcp
  67. "Lots of avoidable mistakes.
  68. Name was stated of a different child.
  69. Wording of some sections weren't appropriate.
  70. Still haven't got one
  71. The senco wasn't fully trained in implementing the plan or how to complete the paperwork properly. Server delays as well due to staff illnesses and lack of communication from principal officers
  72. Challenges from Senar, and professional staff around us and school
  73. Staff at school and social workers/support staff all appear to disregard information. Application through the GP has been slow, and needs irrelevant further assessments, which is further delaying the child from receiving any support.
  74. Health representatives were never present
  75. I was given incorrect information that I can't name any special needs school that I must see if my son meets the targets set out in the end plan then I can request a change this wasn't done when I provided evidence that the school isn't suitable to meet his needs and the teachers haven't a clue about autism at all.
  76. We were told because our child is not falling behind in school work she would not get one
  77. As I said before SENAR will not put anything into an ehcp that will cost money to implement.
  78. I had to do a parental request. Plans are not being finalised. Just have drafts months later
  79. Some professionals were very poor with their attitudes towards us as a family
  80. Educational psychologist actively discouraged specialist provision. Timings are shocking. Having to chase people constantly. People not returning the call. The actual wait. Regardless of how much information I send in relation to annual reviews or requests it often comes back incorrect. If returned at all. I have had one family with all siblings with the same diagnosis the eldest child has an EHC but the younger siblings have been refused, even though it is a life limiting condition that requires daily support above quality first teaching.
  82. Applications lost, timescales not met poor drafts
  83. Struggling to get the support with it
  84. Original statement was vague and immeasurable
  85. At first, my children had a mainstream school named in provision, when specialist provision had been requested.
  86. Lack of understanding, unwillingness to listen to parent view despite us knowing the child best
  87. Once the draft was generated our principal officer went off for several weeks and the process degenerated from there.
  88. SENAR principal decision maker said it was mental Health need and referred to Family Support team.(unnecessary and not appropriate action to assess need/meet need)
  89. Refusal to assess, then refusal to issue a plan
  90. The council refused to assess so we had to go to tribunal. We won the case.
  91. The whole experience for parents poor not and equal say too much experts having to chase reports from specialist

92. Awaiting draft
93. No response from senar
94. "I could write a novel on the challenges we faced and it left myself and my husband in a very poor state of mental and physical health, close to losing one of our jobs and our house. We have still not fully recovered from the trauma and poor treatment we received and this was 2 years ago.
95. One one hand we had the mainstream primary school saying our son's needs were too severe for them to manage and they would have to permanently exclude him. We then had the LA professionals who told us first of all we couldn't apply for an EHCP as parents (a lie) and then said our son's needs could be met at his mainstream school when it was blatantly obvious that he needed a special school environment.
96. Refusals to assess and the waste of time that was mediation later, we saw a solicitor and the head of the mainstream school took things into her own hands and spoke to the most senior person at the LA. The ehcp process was finally started 6 months after we had been 'allowed to apply.
97. We were then told no places were available at a special school and we may get a few hours a week of a tutor. The mainstream school were helpful and tried to continue 121 teaching but we were often called to collect our son early.
98. The LA then tried to tell me that things would be delayed because of Christmas, again a lie as I knew this legally was incorrect. When I called them out on it, the response was 'oh, you know your stuff.
99. Finally a space at a special school became available and the ehcp completed but not before our whole family had suffered to the point of near breakdown (I was signed off work for 4 weeks due to the stress).
100. I could go on with numerous examples but you have asked for brief details. "
101. Lack of knowledge about how it should be written and what should be included by senar staff
102. The dual registered school that was supposed to help/support did not have enough skilled staff or experienced SENCO to assist with any part of the EHC process. Two years wasted.
103. It took 16 months to be completed. My son had no support for his first year in school despite the assessment being requested in the January before he started school
104. I was told a mainstream school could support my child's needs and plan but they couldn't so I had to change the placement
105. Declined!
106. Social Care did not supply information when requested, despite my son being known to the service. SENAR then went ahead and approved the EHCP despite my, and the school's, objections that it was incomplete. I NEVER received a final version, neither did his school. This took over 2 years to rectify.
107. Senco did not register cat team
108. No support or reasonable adjustments
109. assessment failed "
110. NO support from SENAR. There were supposed to be formal procedures in place for times documents were supposed to be processed, meetings etc and we had nothing. Communication was non-existent and our SENAR officer changed 4 times during the time of the EHCP. The deadline for when we were due to have a meeting to finalise the EHCP with all the professionals passed and when I chased I was told it wasn't necessary. We were told SENAR staff were signed off sick or with stress and we never knew who we would get through to when we called - it was shambolic and highly stressful. We completed everything we needed to, on time and as directed - we did not get the support or the service required from SENAR and BCC.
111. No
112. Changing from the Statement of Educational Needs to the draft and then the final EHCP took longer than the guidelines said.
113. Getting support specified and quantified required a lot of insistence from myself that the plan was edited online with the law.
114. Time lines from SENAR were not adhered to and communication was strained. My son was the first batch in bham to be converted. The initial process took nearly 18 mths to compete due to inconsistency with the most important sections being written out to a poor quality of grammar and with key areas of needs not being entered into the plan. E.g my son needed continuation of OT but it was omitted from the plan as funding wasn't going to be given. In my view, the need should not have been omitted as it was identified as an essential part of his learning. Even if funding wasn't given, the need remains. The conversion changed hands (principle officer) several times. By the time it came to review the EHCP, the document was still in draft. By the time the first EHCP was finished, it was out of date as my son had developed a serious health condition and was now in a transition phase at school. Even the EHCP that was reviewed at Easter 2018 has not been recieved with amendments and dates updated.
115. However I felt during the process there was little support to understand the process and
116. Wasn't accurate had to chase a lot to get it amended
117. Not listening to parents, just seemed to be a paper exercise
118. Two refusal to assess for a EHCP although my son had been out of school for nearly a year and was in an adolescent psychiatric hospital due to having a mental breakdown after not coping at mainstream school but being made to attend an environment he could not cope with
119. As before, the school are reluctant to have a child with a specific plan.
120. Initially when transitioning from statement to EHCP none of the professionals seemed to know what they were doing. There was poor communication with parents to establish what we are eligible for - local offer and personal budget were quickly skimmed over or we were advised we couldn't do anything with that.
121. It's too complicated
122. Currently 2.5 years out of date
123. Agreeing to assess
124. Trying to get reports and information from professionals
125. Timescales and targets
126. Getting help and advice
127. Trying to get the right things put into the plan"
128. Sections where not completed correctly and important information missing
129. See q1
130. The school said no even though forward thinking a drs supported me. I have found out after 3 attempts my son is not even registered under the CAT team and the Ed Syhc not been out to him
131. Guidance on completing the plan was not clear.
132. Needs identified by parents did not make it into plan
133. As previous
134. I had to make a parental request for a statement as the senior/mainstream primary school would not make the referral. He had been on school action/school plus for 3 yrs but the school were refusing to make reasonable adjustments even though the adjustments had been recommended by the CAT team, BSS and SALT.

135. The reviews of the statement have always been an issue as schools do not have the capacity or capability to undertake the reviews. His switch from a statement to a ehc plan was undertaken by a specialist independent school who delayed it for over a year and once all the documents and meeting were undertaken, did not submit the transfer documents for 20+ weeks. This has caused my son to have inadequate provision thought his educational experience. His ehc plan was due for review in September but no plans are in place for this to be undertaken even though he leaves secondary provision this academic year. "
136. The initial application by the school was grossly mismanaged and our experience with SENAR was very stressful and badly managed. SENAR repeatedly missed deadlines, their communication was very poor, there was long-term absences of case worker and no alternative contact provided. We could continue with the challenges but you have asked for brief details.
137. No response to any communication apart from automated responses and very large delays. Minimum 9 weeks
138. It took over 2 years just to get acceptance to assess the denied twice for medical reasons? So what's the point in the health section? Finally received ehcp in the 1st year of college and whilst useful now it was most definitely needed whilst at school and I truly believe her exam results would of been better as the appropriate support would of been in place?!

## Appendix D

### Q10 - If you could have changed one thing in relation to the EHC Plan process, what would that have been?

1. To educate all of those involved on implications of acquired brain injury.
2. The LA needs to apply the law
3. Better leadership by BCC, if it had not been for emails from me copying in council directors it would have fallen apart on both times
4. To make it easier!!!
5. Advice and support for me and my child more readily available. I only found out about SENDIASS after I had been failed for years and then they got involved and were able to sort it all out.
6. Mt son used to have a statement and was changed over to an EHCP he didn't have new assessments done
7. Adherence to the timelines and protocol.
8. Be eligible for all no matter if in uni
9. For it not to take so long
10. It takes so long for SENAR to send out draft EHCP and make amendments that time you get the final plan they can be outdated. My son's current plan was 2 years out of date due to SENAR slow to up-date 2 review meetings I had. This meant son's epilepsy was not even identified. Or that my son was under the care of an Oncologist.
11. Faster more streamlined service
12. Being more knowledgeable
13. Process is too long and doesn't involve parents enough
14. If your child has a diagnosis off autism you should get a ehc plan asap
15. My child started at Nursery School at 2 years old and the school started the assessment then but health and CDC would not see him until he was 3. That would need to be quicker as this delayed his start into Primary School.
16. The whole process took a long time from the initial request to the statement being issued. So maybe shorter time frames for certain things to be done.
17. LEA to listen to parents and not fight against them. Just give the support needed instead of making it stressful and a fight.
18. "Assessment would be thorough
19. Parent and child view taken seriously"
20. To be offered it sooner.
21. The time it takes to receive correspondence
22. Timescale which was exceeded.
23. I would have advocated better for my son and made sure I got everything added in the ehcp which is a need for my son. I only realised afterwards how much legal weight and ehcp carries.
24. Doing it myself straight away when my son was diagnosed with autism and not listening to nursery senco who misinformed me
25. better resourced
26. go back to statements
27. sendiass are good they need lots more assessors - why are we spending 25 million of children being sent out of the second city we need more provision- why are schools
28. To fast track a little bit more rather than a 18 months wait because as parents whose child needs extra care and funding we are desperate to get them into special school or get them one to one support so they can get as much as other children in schools and with that help they are able to progress and develop a bit faster. Without the plan there is no funding and without the funding there is no support and help and without the help my child is not able to receive the care and support he needs which will help him to develop
29. Parents have a voice...listen to them!
30. Open & honest information
31. People knowing what the law is
32. Better support through the process "
33. The people who work in Senar could try to sound like they care about children's education and wellbeing. They don't appear to care at all.
34. Correct legal process being followed
35. That families aren't actively discouraged by BCC staff from starting the EHC plan process but are supported with open and transparent information and timely responses.
36. Better qualified staff who have a vested interest in getting the plan right. They need to to be an advocate for the child's needs rather than the school's policies. More information is needed for parents regarding the local offer and direct payments as they appear to be shrouded in mystery.
37. For the school to have identified the problem sooner.
38. More understanding needed
39. Time scales. There are too many hoops to jump through. We parents of send children have enough on our hands without having to fight for tools that allow our children the basic right such as education.
40. Have an outside agency write the plan
41. There needs to be a limit on how long children have to wait for a diagnosis and funding. The whole process of diagnosis and obtaining funding should take no longer than 6 months.
42. To be a bit more faster response."
43. It is very education focussed as it is organised by the school which means that health needs outside of education were not addressed in detail. Getting feedback from SENAR in a more timely manner would also be appreciated"
44. The time it took to get my child the plan and to be a quicker process as all evidence was there

45. Lengthy
46. That SENAR listened to the changes that were needed, instead of trying to make changes without informing us.
47. Not having to continually chase and coordinate the parties involved and that the actions within the plan were monitored by the authorities.
48. SENAR are slow to make changes when required
49. At the moment the time it takes to get a response when requesting one
50. Process quicker by bcc
51. Refuse to assess first
52. clear and streamlined process with clear guidelines and pathways explained to parents and staff
53. Do you educational provider was a meeting I need
54. Time frame children are left way too long to struggle
55. Nothing
56. More knowledge when completing & more support from SEND.
57. The whole assessment process needs to be followed in a lawful way.
58. "For the parents to have had more help from the authority and good communication.
59. Parents could never get through to their principal officer. Messages were taken hardly no one communicated.
60. Lies were told too."
61. Make it easier
62. There are so many. Maybe having a authority who actually put the Needs of the child first rather than seeing ehcp as a paper exercise
63. I would have made sure that ALL agencies involved were at the meetings and contributed their information and evaluations of my son. Only education bothered to attend
64. The LEA staff would have turned up to any review or meeting even once in the whole process
65. The LEA would have carried out their legal duty to reassess my child
66. To have a single named worker who manages my child's EHCP from day one, and knows my child
67. For it to be completed in a timely manner, not over 18 months late, leaving my child in limbo for two academic years
68. The LEA has removed medical provision, and doesn't bother to liaise with the local NHS to source appropriate medical input.
69. That constructive criticism or negative things that have happened weren't omitted or reworded wrongly between the meeting and the finished article
70. Being more honest and transparent about the assessment process, instead of cutting corners to save money.
71. I would actually like the medical professionals involved to attend the meeting instead of me trying to explain everything to the teachers
72. More presence and input from a range of professionals including SENAR, health and social care.
73. the time frame and more communication
74. "Our autistic son EHC was delayed in giving to our choice of school so he was not placed in September but in January at a school further away.
75. So no delays in the process
76. More specific involving more people less they stand no chance comments there is no money, education focussing on qualifications not on learning outcomes
77. The speed
78. None didn't have any problems
79. Just a clearer process
80. Let parents do them at not the senco from mainstream school when they obviously don't have a clue what they are doing
81. Law and regulations followed
82. The SENAR it's crap
83. Cut out the school
84. The time taken to gain a response, alongside the number of external agencies that had to be involved before an application was agreed to.
85. To make sure the Send officer for the school is there
86. Make it more accessible and less tied up in needing professional jargon to get anywhere with the application
87. Timescales
88. More help in filling the form in
89. Needs to be accessible
90. Better communication and accountability for staff dealing with child's plan
91. More support for parents, no judgement, no disbelieving, understanding of autism and how it affects everyday life and school life.
92. Been listened to. Had knowledgeable staff support the process, or even act on suspicions years ago rather than let children struggle for years. No One seems to want to listen and act.
93. Been more forceful with health representatives
94. To be completed within a shorter time frame
95. To have it offered or explained in the first place
96. Quickly process
97. That there was more input from health. It is a very education led process. Aside from his Physio there is no input or partnership working from the other myriad of health professionals involved with him.
98. Main stream school and direct payment plus a care plan as Shakeel requires it
99. Time process, far to long
100. The time it takes
101. Put people into SENAR who have an understanding of special needs and not pen pushers who have no grasp of the send code of practice.
102. Local authority sticking to legal timescales
103. Time consuming and soul destroying process
104. "The time it took to get one implemented the wait and see process. Every child with a diagnosis of Autism and Learning Disabilities should have an EHC plan in place from the very beginning and not years later or none at all.
105. People would have met with me and listened to me and professionals who knew him the most
106. Common sense. Some professionals had another agenda and came to the situation trying to discourage ehcp.
107. Better communication with SENAR from a school perspective, whilst I appreciate the difficulties that they face and the huge caseloads principal offers hold, along with the logistical side of managing SENAR I do feel that schools are trying their best to support parents in a range of situations, then they hit a brick wall in terms of SENAR. I also recognise that the financial side of SEND means that schools budgets along with LA budget is tight, however we as a school fund additional support such as buying extra hours form outside agencies e.g Ed psych service, PSS, speech and language therapists, OT's etc etc only to be met with a lack of understanding in relation to the reality of funding this in schools. I keep detailed costed provision maps for all provision above quality first teaching to highlight the costs and when relevant complete the required CRISP funding process, however additional money is often refused, even though I can evidence the costs of provisions, this puts an even bigger strain on schools offers of additional support. On a positive note I would like to recognise the outstanding service that we receive from Sue Smith (PSS) and Cherelle McDonald (Ed Psychologist) they are invaluable to us at school as they work with our children and families to support their progress and individual needs.
108. Better parental support while undertaking process
109. Make it easier for parents to fill in and also for schools to have to put one in place
110. More of an effective document

111. To have had more professionals present.
112. Lengthy process
113. Timescales
114. SENAR need to be more communicative regarding the status of applications and more effective at processing applications from one stage to the next.
115. The lack of information from SENAR and the time it took to have a school placement
116. Correct procedure followed, ie Education psychology assessment prior to DNA decision
117. Strict penalties for the law being broken by SENAR (parents are having to become experts in the law to fight for what their children are legally entitled to.)
118. The Council should have assessed my son and not forced us to go to tribunal. We received support from his paediatrician and CAMHS worker who advised us to apply for assessment. SENAR disregarded medical advice and rejected the request for assessment made by school without seeing my son.
119. Get everyone together or use electronic to collate before meeting and commitment for everyone to attend
120. N/A it was effective and explained to me with a fine tooth comb
121. Awaiting draft still
122. The people involved that never met my son yet held up the process numerous times just because they could
123. They'd have called back
124. I underwent the process with a senco, however I would've struggled to complete it by myself. Even now I cannot understand a great deal of the EHCP
125. That the LA would acknowledge that parents actually know their children and their difficulties and we have names rather than just mum and dad.
126. I wish children would be given one automatically when they receive an autism diagnosis. It is so much stress for parents. My main reason that I am unsure whether to go for one is that I am not sure whether the stress it will incur is justified by the likelihood he will get one. I feel he is unlikely to get one at the moment.
127. Input from a knowledgeable representative to help write it
128. Speed
129. More transparent process.
130. Nothing
131. Stop school denying there is an issue and LA denying sen kids struggle
132. No change anything school had put on partimes which hour a day but only play in class on his own with two t a even days couldn't cope with it decided he couldn't be done long term as the t a were taken away other classes be couldn't cope main class room were too many class32he just couldn't cope need in school had small groups which is in doing okay very delay because in of school
133. That representative professionals actually turned up to the meetings they ought to.
134. To access cat team and ed psych with full senco support
135. That the SENAR officer allocated to us was consistent, professional and supportive in their approach. We felt constantly undermined, in the dark and had to muddle through, chase CONSTANTLY for any information or support.
136. N/a
137. For it to have been finalised quicker than it was
138. Look at the child's needs rather than use the CRISP to determine funding.
139. Quicker. Online access to progress.
140. To of had better communication with important parts of the plan not being omitted. Sorry but I have another. I was put under tremendous stress as I was constantly emailing or going through mediation. This should never have happened. I had to make sure the EHCP was right as my son is now in a specialist post 19 education so it was vital that the EHCP was right in order to get this provision
141. Timescales, due to BCC not having enough funds to get enough staff to respond it took longer than expected and not having enough schools who are inclusive meant my child had to wait for a placement who could meet his needs
142. It felt like EVERYONE is turned down then only if you make a fuss do you get listened to
143. More input from parents
144. That somebody listened to me.
145. Getting an EHCP when first requested as then he could have been placed in an appropriate setting rather than making him continue at a setting that he could not cope with
146. School being more supportive
147. Transport should be included because how can you educate a child if the child,(my son),can't get to school to be educated. He is legally meant to attend education until 18, so this should be carried out until then. There should be more people in the annual review and must be transparency to make things easier to share info for professionals that can't attend. All professionals should attend unless a good enough reason provided. There should also be someone there from the LA to make sure everything is in the correct box and explain to parents who maybe don't talk English or have difficulties understanding an AR.
148. Professionals actually turning up for first one
149. More information regarding personal budget and local offer. Actual annual reviews!
150. That the parents views are actually listened to and the future of the child is looked into... what's fine at the moment might not be ok in secondary school life
151. Ease of access and knowledge of staff
152. Keeping it up to date
153. To have been explained more to in the beginning
154. Better communication
155. Make sure it's water tight and if a child requires a guide it's noted down
156. Principal officer
157. More than one I'm afraid.
158. Be nominated one worker on the case and this worker be contactable.
159. The timescale much quicker. "
160. Have them listen to me and my child instead of trusting the school.
161. More clarity
162. Listened to
163. That the process is actually followed and trained staff with knowledge and experience undertake the review. Parental views need to be considered in more detail and professionals need to stop seeing parents as a hindrance (we are not difficult or challenging, we want what is best for our children and are tired of having to fight continuously for support)
164. Meeting the EHCP deadlines. The whole process from initial application to getting the plan took 2 years.
165. N/A
166. Communication definitely. Feeling frustration when your child is attending school less than 2 hours a day and no one appears to be interested to helping provide an education is upsetting and exhausting for the constant chasing.
167. That the sendco would have listened to my concerns about how far behind my daughter was academically and applied to access sooner instead of fighting for over 2 years and seeing her deteriorate and suffer on going mental health problems as a result.

## Appendix E

### Q13 - If you could have changed one thing in relation to the SENAR service, what would that have been?

1. The LA needs to apply the law
2. Clear instruction for desired setting were ignored and assumptions were made. Schools we approached without our request or authority.
3. Make it easier for parents to access information and discuss plan
4. SENAR could improve by being more transparent and responsive
5. They don't write rubbish EHCPs
6. For them to attend meetings, to reply to emails and answer the phone calls
7. For them to do their job and not need constant reminding by parent!
8. To have more contact with them and not take so long with the ehc plan
9. Someone to always be available to answer the phone . If e mails are sent at least an acknowledgement of receipt of email within 24hrs and with a response to an issue within 72hrs.
10. To know who they are and what they do
11. Contact with parents is poor. Needs to be more communication and clarity on processes
12. Be more understanding
13. They are very slow. You have to chase everything and then they asked for additional information about my son which we had already submitted with the plan.
14. Proper contact, face to face meetings, being kept updated and being listened to.
15. Challenge schools more robustly
16. That I didn't have social services call us up to question my daughters safety, upon receipt of pictures of her condition that were shared with SENAR to highlight her issues. That they had actually followed up what they could do for us when they said.
17. Increase the number of people working to share the workload. Current drafts can take 20 weeks to come back. That's nearly half a year and much too long for a child needing support.
18. Telephones to be answered.
19. They are not accessible at all, they don't meet any of the legal deadlines in terms of plans. They never give you the correct advice or the legal rights as parents we have,
20. If it wasn't for the rep from senar my sons plan wouldn't be any good
21. Under resourced
22. that they actually get back to parents they just are not interested in helping parents
23. I am new to the area and job as Head of Resource Base and have e-mailed SENAR in the hope that I could have a meeting and understand how SENAR works so that I can best support the school in providing for the pupils. I have not had a response. Whenever I have asked people there seems to be that nod of acceptance that this is the norm.
24. SENAR I personally had an experience with them concerning my child's school choice when they sent me a letter saying cherry oak had accepted him but they really didn't , I had to personally call up cherry oak and resolve matters with them.  
How can Senar send me a letter saying a school accepted my child when the school had not even made a decision about my son.  
That shows there is a lack of concern or someone is negligent about their work  
If cherry oak had refused my child what would senar have to say about the letter they send me remains a question
25. in my mind.  
As above, that they could try caring. They could also try being pro-active and problem-solving. They don't sound like they want a positive outcome.
26. Being able to actually speak to case officer. She NEVER answered a call, returned a message or responded to an email.
27. An openness to discussion and sharing information about our child in a professional and transparent way.
28. They need to be more involved on a local level. Most contact regarding my child is with his school, I have only had to contact senar regarding the initial statement application and when I too the local authority to tribunal for failing to quantify hours on his statement.
29. They couldn't help with my issue and delayed matters further
30. The whole service needs closing down and starting again with staff that understand the struggles of having children with SEND. It's disheartening that you are passed around different key workers.
31. Have someone who communicates with parents
32. Cut down on waiting times to be heard
33. Speed up decisions.
34. The people delivering that service should listen to the parent of the child concerned.
35. Timeliness
36. Is not to keep other in a loop hole and not to waste time of children with special educational needs
37. As said, SENAR should take their guidance from the professionals that have contributed to the EHCP not try to remove all the pertinent information sent to them and thereby making the EHCP less effective and incomplete.
38. Keep a better eye on the journey of the child particularly during transitional stages. monitoring and review actions taken by the school and appropriately step in when it is blatantly obvious that actions taken are not necessarily in the best interest of the child and follow through until these actions have been rectified to ensure children are not left disadvantaged and actually reaching their full potential.
39. Their efficiency and promptness.
40. Communication
41. not applicable
42. The whole organisation was fully managed
43. You can never contact the relevant principal officer. They don't attend meetings. My son is now in a special school that can't meet needs. Senar have been no support at all. They have given no advice as to where he should be placed. Doesn't reply to emails. Senar are a joke
44. Nothing
45. Severe lack of communication & constant staff shortages, arrogance that as a parent you don't know what's best for your child.
46. They need to be honest with families about what is happening. They lose paperwork and take months to provide what parents need.
47. Better communication from high up principal officers who are not doing their job properly.  
The whole system is wrong  
Identification of SEN takes too long.  
Waiting lists for services far too long.  
Once referrals are made sometimes they cannot be processed due to school age of child this causes huge delays  
Health visitors on the ground are now being told that

- children over the age of 2 and a half are not to be counted in data  
Not enough money being given overall  
Speech and language service is a joke
48. For them to actually do their job
  49. A huge shift in culture from being gatekeepers, whose job is to minimise costs to the LEA, to actually working in the interest of children and families
  50. It's very slow. No-one seems to answer the phone , people never available to talk , don't get back to you
  51. My son was in a setting that did not adequately support his needs for primary and he is significantly behind. SENAR failed to identify this.
  52. Well at first they kind of dragged their feet a little and didn't give the school enough funding to be able to pay for a suited TA, which resulted in my son starting the school in January rather than September. Since then though my relation with them, thanks to one individual in particular has been tremendous.
  53. More efficient in updating EHC plans following reviews. In most cases we are reviewing plans that are out of date and have not been updated following last year's reviews.
  54. The service should be more understanding towards parents views and needs
  55. More approachable staff. Jelena did not appreciate parents contacting her
  56. More communication from them
  57. Lack of transparency
  58. Quicker
  59. It's useless hard to get hold of
  60. Completely inept Department that needs to be closed down and a service fit for purpose delivered
  61. Everything needs to be change, there's a disaster institute
  62. Make them more user friendly and better able to help parents
  63. I have had no support from any agency. My son is a Birmingham child going to a Solihull school as far as I can tell this means zero support from either authority.
  64. Make sure their read and respond to their emails
  65. N/a
  66. Skill set of staff
  67. To help my child get an ehc
  68. Better communication more efficiency , not going past dates , giving parents time to reply instead of giving an answer within 14 days yet you only receive paper work within a week of the reply date better system overall
  69. Not got that far
  70. That they answer phone calls
  71. Quicker service
  72. To continue and have some coordination after diagnosis. Fallen out of system of support, told education would support but it has been poor
  73. Quicker process
  74. Very slow, unresponsive service. Named officers changing or leaving with no follow through on our son's plan or ownership of issues. Changes to plans months behind. His plan was amended when he went to secondary school (Sept 2016). He is now in Y9 and we have still not had a copy of an updated EHCP.
  75. For them to meet the timescales for ehc review I had to request one as it was well over 12 months it was supposed to be reviewed in December 2017 yet it wasn't until I asked for one in March and it wasn't until May 2018. I am totally disgusted at how Birmingham city council don't care about meeting the needs of disabled children but just want to save money so they want to keep disabled children in mainstream schools as it's a lot cheaper for them and children services too I requested a needs assessment for my twin boys and myself due to the impact on my wellbeing due to being a single parent and I am under mental health because of the work both boys take. I was refused a carer parent one and told my twins won't be given any services due to them not being severe enough when I asked what is severe the social worker said in a wheelchair or blind which is actually a unlawful statement
  76. To get more support
  77. Being able to speak to someone when I need to
  78. That they treat you like a parent that needs help and support, without judgment
  79. Get in professional staff.
  80. Better communication, sticking to legal timescales with ehcp process. Answering emails.
  81. Reply to emails sent
  82. Having received diagnosis the next step is assessing the Holistic needs of the child. SENAR took too long to get done. Two years before this was done. The Anxiety and Stress and daily manic thoughts going through parents heads is unbelievable. What it's. Will my child meet the requirements. All of these are added pressure that sometimes make life as a parent unbearable and very lonely. The Long Wait needed to Stop the process must be made Quicker and more support Given to Families.
  83. There is such poor communication, no empathy or understanding for families and no knowledge of process or SEND just taken as an admin process than something so essential for children and families
  84. That they can be too aggressive. That they can seem ill informed
  85. Response to emails.  
Response to annual reviews.  
Response to telephone messages.  
More regular updates to schools in relation to how the service is meeting the needs of children so that we can better understand the pressures they face, this would allow schools to offer support to SENAR.
  86. Availability, never had responses to questions or urgent calls, felt ignored
  87. I haven't had any involvement with them
  88. Time it took
  89. They would be more people friendly/child centred.
  90. Easier to contact
  91. To help u to understand he whole process and guide u in filling the form and not say well here is the form now u fill it and when done contact me
  92. Timescale
  93. To listen to the parents
  94. As previously stated their communication was very poor and when we did speak to someone who wasn't dealing with our case the information they could find out was sketchy or incorrect. For example, we were told the EHCP had been sent to schools when in fact they hadn't received it.
  95. SENAR could explain what is happening once the application has be submitted and improve the timing as it so long
  96. Hostile and personal attack from officer. Thankfully changed to another officer and appropriate support offered.
  97. The fact that nothing ever moved forward without us chasing them & making formal complaints about the way our daughter's case was 'managed'
  98. Improve customer service and responsiveness
  99. N/A again when the previous EHCP sorry forgot the name was in-place the working together was spot on, so no issues arose with the new EHCP
  100. Call back when asked to, I phoned time and time again and they were always so vague
  101. That someone would read the notes and at least try and understand
  102. Better communication with parents and other organisations

103. They'd have responded
104. Understanding the process in layman's terms
105. I wouldn't have bothered wasting my time with them and would have gone straight to my solicitor.
106. That they adhere to their timescales
107. Staff that know their job and communicate properly.
108. That was more of them to cope work load as I was one lucky one once decided got ehcp it went smoothly apart for having problem with transport because no guides still weeks start his new school in end I had to in taxi there and back 11 weeks least since sept in on mini bus so doing well just not write so many kids stuck in wrong school which cause problems longer take get ehcp plan sorted finding right place make world difference to kids
109. Actually meet the assessor and have a meeting around the child
110. They did not assume we were happy with the draft EHCP, we were NOT, we objected in writing but this was ignored.
111. To read the professional evidence supporting children More people centred staff to deal with paper work
112. The whole process. Everyone is overworked, stressed or lacking the knowledge to support parents. Its takes 20 mins to get through to the right person.
113. Respond to concerns regarding school not fulfilling EHCP as it hadn't been reviewed by SENAR within the timetable it should have been.
114. Consistency and speed
115. I have answered this previously
116. Timesales
117. More staff so they can actually speak to you and reply to your emails
118. Listen to the parent. Stop the excuses
119. Been taken seriously that my son was struggling and the school was not keeping his needs.
120. That someone would of listened to my daughter's views!
121. A phone call back would be nice
122. Someone from SENAR SHOULD be present at ANNUAL REVIEW. The draft and final should be completed within the statutory timeframe
123. Communication
124. They need more involvement with the EHCP review process as they have more knowledge compared to SEN school staff. They should be an advocate for the child to enable them to get what they need, not a last resort to prevent escalation of the parents frustrations!
125. Tell the truth. Don't twist and turn the reality of the case
126. Availability. Knowledge of staff
127. Everything - though very polite never completed anything on time and where very hard to chase up
128. More communication
129. Better Communication required
130. Work together with travel assist and share information better
131. communication , timescale efficiency
132. A phone number that actually rings out.
133. They could be less rude and listen to us and be more empathetic towards situations.
134. Lack of organisation, training and understanding
135. Enough staff to undertake the role so that there are not always long delays! Better understanding of what the SENAR offer is so that we can have realistic expectations of what is available.
136. Better communication from SENAR in particular from our case worker who was very difficult to contact and was not covered during long term absences.
137. More personal and respectful
138. Clearer information on numbers and distribution of people with hard of hearing difficulties
139. Communication
140. To have 1 principle officer throughout the whole process not 3? Having to relay the same information repeatedly becomes tiring?

## Appendix F

Q17 - What, if anything, do you feel would make co-production more possible for parents and carers? Please give examples.

1. To liaise with professionals that were aware of the implications of certain conditions
2. Co-production will not work as long as LA officers believe they have power over parents
3. Teachers and professionals to listen to parents needs
4. Having a caseworker from SENAR who has more knowledge of my child's case and can suggest strategies for short and long term. A lot of times I feel that unless I am knowledgeable about every single aspect my child will miss out on opportunities. I feel like that I am negotiating or lobbying with the city council rather than receiving a service or support for my child. It is exhausting and stressful because they are supposed to be the experts and not me
5. Transparency
6. Parents are fed up of taking part in consultations with nothing changing.
7. Times to meet working parents as meeting times are not always flexible.
8. Don't know what it is, haven't been asked to participate
9. Maybe who is working with your child going over how they are doing before the meeting would be helpful
10. Listen to the parents we know our children .not all children fit in to certain areas and need more time to be observed over time
11. SENDIASS WORKERS SHOULD BE MORE PROACTIVE PRINCIPAL OFFICERS ATTACHED TO A CHILD NOT A SCHOOL
12. There needs to be more awareness of events taking place where parents' views are heard.
13. More clear outcomes from input, genuine change
14. Communicate rather than people thinking the parents know nothing
15. Wider knowledge of consultations
16. Easier access
17. I'm not even sure what you mean by co-production. There's already enough meaningless jargon in SEND
18. Wider publicity so we know about events. Variety of times and days to suit working parents.
19. The Council recognising the full range of parents and carers with whom to co-produce next steps and who want to collaborate. Currently operational leads appear to only work with their preferred parents and carers and appear to be ignoring the views of others who have expressed alternative views. I've only been invited to one consultation and that was via Health leads not Council leads.
20. Improved parent and carer support in a flexible way that works for parents and carers including those who work and is neighbourhood-focused or school-focused in the case of special schools as appropriate. E.g. making sure

- parents of children newly-diagnosed with autism have timely access to flexible Early Bird or equivalent learning sessions with people they're likely to meet in future instead of being offered a place on a course on the other side of the city a year after diagnosis as I was.
21. Currently services and parent groups are inflexible, geared to non-working parents and it seems Council staff preferences with a paternalistic approach of ""We've always done it like this and we're going to keep doing it like this"" even when there's strong evidence that many parents want something different. Working parents/carers of children with SEND arguably have less access to peer support networks than parents who don't due to work commitments. The Council and Health can work with parents to create more local peer support networks which in turn can help meet local, diverse need.
  22. A genuine commitment to system change to support children with adults and their families instead of focusing solely on financial savings (e.g. Special Needs Transport) "
  23. The consultation I attended was when EHCP's were being initially brought in. Someone gave a big monologue about how it was marvellous and they'd been able to take a more active part in their son's education. They pontificated about direct payments and the local offer and made it all sound amazing. I fell for it hook line and sinker, but so far have failed to be able to access any of this for my child, often being dismissed when I enquire about it. There needs to be a much more open discussion regarding this option and what we are eligible for as I feel somewhat hoodwinked by what I was initially "sold".
  24. We need to be listened to. Don't ignore our voices. We know our children better than any professional. We live this life 24/7
  25. Times of meetings. Some of us work and have to collect kids from school etc.
  26. When it comes to the term parents view they only agree to disagree in the long run
  27. Give parents the information and time they need to digest all relevant information. All parent engagement consultations should be on several days and at several times to ensure that all parents can give their time, whilst still caring for their children.
  28. "I would like to add that although I have answered yes, this has only been within the last few months and do not feel that invites to parent consultations reach far enough within the community as it should. Consultations should maybe split into two for working parents and non-working parents as many working parents miss out on the opportunity to contribute as it is often taken place during the working day and days off or annual leave are already overshadowed by using these days for caring for our children and can be hard to request extra days where employers are not as understanding as they could be.
  29. It is also important to consider the school run for morning starts. 8.30 or 9.00 am starts are not ideal.
  30. Webinars options may also be a good way to interact with those that are unable to attend but may want to contribute."
  31. have not been involved in any consultations
  32. Listen to young people more
  33. More communication & support.
  34. Make sure all parents get one.
  35. "When authorities have parent co production meetings they are not advertised well and people are not given enough time to prepare then the professionals will collect data and say not well attended therefore we have tried to engage but not many attended!
  36. Inviting more parents and listening to what we have to say
  37. That social care and health were legally obliged to attend.
  38. At present it is almost impossible to phone Senar and if your call does get answered, the person you need to speak to is never available.
  39. There is no consistency. My child's EHCP kept being passed to different people
  40. An office you can actually visit?
  41. Listening to parents"
  42. It does feel a little intimidating for parents, don't want to say the wrong thing. Don't understand all the jargon and politics. Always made to feel welcome , but feel out of my depth
  43. If parents want to change child's setting (school) for the interest of the child Senar should agree rather than look at how costly it will be Senar has made our lives v hard and miserable by pretending that they listen to us but will do what is more in tiger interest
  44. A suitable venue and flexible times
  45. Simply put, you are processed with very little input or say and receive the absolute minimum that they feel they can give you
  46. Consistency of child centred approach.
  47. Parents' views being given the priority they deserve, not just ""lip service"" they are the children's advocates and experts.
  48. Improved communication between services and between services and parents.
  49. Real understood how the child learns not focussed on certificates
  50. Making sure not just one disability is represented and that there is no personal agendas
  51. Not a patronising exercise to tick boxes
  52. Make them a regular annual event so we can air our views on how system is working for us
  53. I was not aware of any consultation. As well as no support from anyone we also do not receive any communications
  54. Listen properly to the parents and carers, they are living with the person in question and are the expert on them
  55. More notice given , more informed information , more support parent support groups
  56. Listening to the concerns of the people who spend the time with the children, rather than prioritising the views of the "expert" who met the child once on a good day. Stop discussing the child in relation to others with similar needs, I don't need to know that there are others who are worse, I need support for this child, right now. I need to be listened to.
  57. More frequent meetings to observe the child in various situations and discuss the necessary actions
  58. OT talked about it. Never followed through, no information or letter sent
  59. It will be good for the child.
  60. Again, as with most things it is Education led. Health partners have not participated in pupil-centred annual reviews, except Physio, 1 out of a team of 8 health professionals. No mechanisms to co-produce with health. Feel like it is the same parent-carers/forum all the time that are involved if there is any input asked for.
  61. I wasn't explained how a EHC works and I wasn't informed of my permission when they had educational physocial worker observe and interview my son they did this twice.
  62. If they took more notice of parents
  63. SENAR actually listening to parents instead of trying brow beat parents.
  64. Professionals to know that families are the only ones who know the child he best. It is a life-long job looking after their best interest and the services must respect and communicate more with families. Engage on every level about the services that will impact and support them. And take families Views and Concerns Seriously.
  65. Actually listen and understand different perspectives

66. Co-production. It wasn't that at all. It was a consultation to tell us what they were doing. It was lip service decisions were already made, in a cost cutting way and it didn't matter what was said decisions were made. Pointless
67. Our parents at school are invited to half-termly informal coffee / tea afternoons to facilitate additional support for families, workshops, INSPIRE events etc.
68. For parents of children with an EHC we invite them to attend annual review meetings.
69. We have an open door policy for all parents to facilitate relevant support for children at all times."
70. "At a range of times and dates to involve more people
71. That views are acted on and that things are done with parents not conversations and then do whatever is easiest and cheapest
72. Childcare for parents with younger siblings
73. Co-production at easily accessible venues? Local special schools for example"
74. I am also a SENCO so can easily understand the process. Parents can only be involved in the process if they understand, and do not feel intimidated.
75. By having competent professionals who can do their job properly. I was lucky to have this in my daughter's case.
76. Listening to parents views first - I could have told you the headlines of the SEND report before they were published, yet it took the report to make commissioners and providers listen
77. Have full information regarding the coproduction. Also insure the consultation is child friendly as most parents have childcare issues, which makes it difficult for them to attend consultations
78. Information sharing in realistic time frame to enable digestion and an informed input in co-production. It is desperately needed to improve our city and children's chances
79. N/A my daughter's SEN school is very good in-keeping us parents informed and happy to assist/ provide information when requested
80. When given dates are given for anything it's either too late for me make plans or it's during the day only and I work full time
81. For health professionals to listen and not talk down to parents who see their child's difficulties day in day out
82. Nobody listens, and don't act on what they say needs to be done
83. To be listened to.to be heard and to acknowledge parents views
84. Professionals need to listen and further training on sen needs
85. Sharing information.
86. Meetings outside of the hours I work, the online consultation felt like you were led to certain answers. There was no invitation to take part I discovered it from a friend.
87. Advocates for parents who understand jargon and legal bumpf
88. The old Parent Carer Forum was effective, but sadly no longer exists. Any new Forum must be genuinely representative of all disabilities to be credible. The Local Authority needs to have a dedicated Parent Participation Worker, rather than this role being tacked on to another job as an afterthought.
89. Provide to parents/carers reports in advance of meetings. I was refused copies of Ed Psych reports written about my child and CAT team reports.
90. More communication. Emails are not responded to. Calls being returned can take weeks.
91. "Letters, phone calls, emails invites to consultations that happen, if the council don't understand our children's need don't be scared to say they don't understand just ask us parents to help them understand so all kids are better in the long run. Communication is key.
92. But not by putting it on Twitter or Facebook or any other social media platform not all parents can access this. For many reasons, 1 main reason is cultural differences."
93. More support to understand the whole process.
94. Not involved in one
95. Talk to parents, they know the child better
96. Engage parent and carers. Listen to them and act upon what they say
97. Being invited in the first place
98. As a parent who has a child who has had a statement and now EHCP for 8 years, I've no idea what this is which concerns me somewhat.
99. Information more available and reliable available contact personnel
100. People to liaise with parents over decisions and responding to issues raised.
101. More information and more parents consulted with and actually listened to
102. Better communication
103. Be honest with parents
104. feeling that we are understood and that our opinions are right for the child in question not everybody else's children
105. Parents are listened to more
106. Stop treating us like the enemy! Parents often spend a lot of time researching their children's disabilities and have a great understanding of the challenges their children face and things that do and don't work. We would be an excellent sounding board and partner if given the chance. Instead we are treated poorly at every opportunity! Actually listening to what parents say and taking on board their opinions could really transform the service that are provided. Building positive relationships with parents rather than trying to do anything but work with them would be beneficial and reduce a lot of work and ultimately a lot of heart ache and pain both the children and whole family.
107. We are not aware of parent consultations existence so to be informed about them and given the opportunity to participate.
108. Parents and carers being listened to, respected and valued as knowing their child the best so the services using our knowledge and experiences to provide the best service possible for our children.

## Appendix G

Q20 – Parents were asked to tell us about their overall experience of telling their child's story and then did they have any suggestions for ways that we could improve this process?

1. To liaise with the professionals that know about certain conditions
2. When we describe situations, we are not always believed.
3. In my case my child moved to Birmingham in year 6. So in addition to finding a primary school the city council should have also started the secondary school transition process. I was the one who alerted SENAR about this and

- requested the paperwork. Otherwise we would have missed the end of October deadline for sharing our preferences. These processes should be aligned and revolve around the child and not around the way SENAR is structured
4. Share information with parental consent
  5. Autism passport. One page profile. Short video that can be shown so no need to explain the story over and over and over again.
  6. As Birmingham has such a high number of children with SEND, senar principle officers should have the responsibility of fewer schools as they can offer a more child centred approach in ensuring services meet the child's needs.
  7. Making the process for diagnosis quicker in order for the child and parents too access support. There is no point in telling parents their child may be autistic and then leaving them years before diagnosis. Creates frustration, depression and isolation
  8. Teachers talking to each other before children move classes so other teachers know the child properly
  9. People don't pass on information and paper work and no one checks that they are doing their job
  10. Principal officer attached to child not a school
  11. Joint working. Have some sort of "passport" that can be given to all agencies so that parents do not have to keep repeating the details about their child.
  12. Having parents advise parents it makes sense
  13. This isn't the biggest issue, I will tell it 100 times as long as my child gets the support they need
  14. I have 3 disabled children. One I can't get to school and he is severely disabled. come and actually see the families rather than just making random judgements
  15. Parents need to be listened to
  16. Referrals for SaLT from community services & Birmingham children's hospital have been lengthy & we are still waiting to be seen by community again more than 1yr after BCH said SaLT needed to reassess. Health visitor less than helpful & not supportive. No support from social care, no support or resources provided by anyone. We have told our story over & over again & still got nowhere
  17. Read case notes, prepare for meetings.
  18. Professionals looking at files before appointments. Better record keeping.
  19. Ensuring all services get the difference as well as crossover between LD and autism i.e. that autism isn't an LD in itself.
  20. That services adopt one flexible child passport/'All About Me' format across the partnership and ensure that individuals/families can update these easily as-and-when needed.
  21. Improved staff training in SEND across the service.
  22. Encourage children's autonomy and decision-making capacity as far as possible - so it's not just a parent's view that's captured.
  23. I'm happy to tell his story, I'd sing it from the roof tops if needs be. You cannot expect every teacher/support staff/CAT team/Ed Psych to remember every aspect of every child's story. I/we are his advocate and are best served to quantify his experience. I want people to know how badly he was treated, how a head teacher treated him with disdain, wanting him gone from his school. I want people to know about the amazing people who have offered exceptional support and the others who did not. I want to share our experience and see that there is good and bad, positive and negative. So, I want people to not be afraid to ask. If I don't want to answer I will let them know, but I'm the whole I would prefer to give my version of his story, complete and unabridged, because despite his challenges, my boy is amazing and always has been.
  24. Being more understanding and helpful
  25. Read the files!
  26. Have 1 caseworker at the start to discuss the child & put some sort of book together that reflects the child & each professional that assesses the child adds their report to the book
  27. Teams working together
  28. Everyone needs to work together - schools, SENAR, social services, the police, NHS. I am quite educated and a proactive person but even I feel like I'm banging my head against a brick wall and getting nowhere.
  29. I enjoying talking about my son and telling people/professionals about the amazing things he does.
  30. Once a file is created for a child with details of their disability etc. it should be shared and updated rather than every area having their own files.
  31. Is to act upon an actually see the existence of the difficulties of the child an help them get the right support and provision
  32. Share information on a database and accuracy of details recorded
  33. All parties who engage or will engage with my son should be fully briefed on the ECHP and his educational history. This would avoid us having to repeat his story and our journey, over and over again. It would allow the relevant parties to focus on their specific area of interest.
  34. A central system that can be accessed with the information that is updated when changes occur. This should be read by the individual and then any further questions asked for clarity or if the parent carer would like to add, rather than having to start from the beginning
  35. Shared information between professionals
  36. streamlined referral process and a way for parents/patients to check on its progress including for operations, therapy or MRI etc "
  37. Actually have knowledgeable staff available that genuinely care about the needs of the child & what is best, rather than what is the easiest paperwork to fill in.
  38. Departments need to talk to each other. Especially social care. The family support workers can't even refer to the disabilities team. Its a mess.
  39. Not have to repeat it over and over again and not to be fobbed as as all children don't like school.
  40. Say it once.
  41. Senar staff see themselves as gatekeepers whose main function is to defend the LEA from financial costs
  42. Remove the hostile atmosphere"
  43. None
  44. I am always fighting for the correct support
  45. It's meant to keep everything in the same place but you still constantly have to repeat yourself
  46. Departments just don't communicate, you have to go through everything every time you see someone new.
  47. Parents often report having to tell their child's story over and over again. Ensuring professionals share family information and actually take the time to read it before meeting with a family!
  48. All share same data system
  49. It doesn't take long for someone to read notes before an appointment and sharing info across the board
  50. Get people who understand
  51. Proper support for families
  52. Better networking between professionals
  53. No one has ever asked for a story. There are many aspects of my sons ASC that O struggle with but I have received no offers of support from any part of the Partnership. I find it interesting that local authorities are supposedly working together and yet living and schooling in different LAs means that no part of the "partnership" has ever been in contact.
  54. A single file, kept updated by all external agencies.

55. Why can't you use a one page profile to give you the history anyone for the positive?
56. Listen properly. We are the best expert on how a person lives with their condition
57. Health talking to education
58. Should only need to say it all once, it should be recorded somewhere
59. Once you have told the main story it should be included as introduction to child as standard then instead of repeating the whole story every time you could just add to it as and when things change. For example you could have this is my story the a subsection as a continuation: since our last review I have now developed (x, y and z) skills and now I no longer need help with (a b or c)
60. Better communication , more understanding of the situation
61. Listen. Take notes. Stop cancelling meetings, or turning up to discuss issues with a short window of time to do so. These issues take time to discuss, and the fact that children are going undiagnosed, and schools are accepting that 11yr olds cannot read or write is appalling.
62. Improve time for diagnosis
63. Single assessment process that cuts across organisations
64. Every school teacher n staff need to be more active on this process
65. Joined up systems that can be accessed by all involved. Multi-disciplinary meetings that are attended. System is too fragmented and reliant on parent/carers to pass on/remember crucial information.
66. If all the agency's contracted each other better
67. Tell the story once would be great joined up working between agencies would help this happen
68. Departments should try communicating with each other.
69. That school, camhs, social care, crisis team and home treatment team all have accurately written info checked by parents. Too much factually incorrect info gets shared around.
70. "Cooperation and Communication between services. Professionals should the information there and stop having us repeat the experience of the beginning of the Painful Diagnosis Journey over.
71. Joined up thinking. All professionals, schools and everyone working on one system they all have access to. When you have an appointment the professionals would have already read it online file where everyone has submitted to and know what is going on. Every service works in isolation at the moment. The child is not in the centre of this process.
72. During the annual review / school meeting process we encourage parents to update us rather than focus on what they have already told us. All meetings with parents are then evaluated.
73. Not having to go over everything constantly
74. Tell it once does not happen. Even at the same appointment - there is no shared info
75. The story should be available for everyone to read, and to be understood needs to be detailed.
76. Have a system where the worker are informed as it become tiring when u have to keep repeating
77. Consistency in key workers, robust files kept, files being kept up to date. Basic caseload management would be a good start
78. Make the system centralised to ensure it's once we have to tell the same story. Telling your child's story is very hard and at times heart-breaking for parents.
79. Professionals listening to each other's expertise and looking at holistic approach rather than lip service.
80. Global system for sharing information and/ or family's to have records printed off and made into a storybook/ file
81. Class teachers to be more aware of special needs.
82. A site that all can access
83. Treat every child as unique as they are, this is their life we are trying to improve
84. Listen and acknowledge that parents know their child enough to respond with empathy.
85. Better ways of communicating between services
86. I haven't had many opportunities
87. Good communication, it's not rocket science.
88. There is too much emphasis on the negative in front of the children. Autism assumed to be negative. My son's self-esteem was badly affected by the diagnosis process and he was only three at the time.
89. Keep the same review officer – has changed every year if is
90. More experienced staff with understanding of mental health & wellbeing.
91. It self need to talking more everyone involved don't feel this always case which delay sorting plans out.
92. I'm lucky to have a good Senco at my son's school but I feel the Senar Service have no idea about my son. They have never met him, they don't meet the teacher and they don't monitor any outcomes.
93. Practitioners actually reading a child's Ond Page Profile, where one exists.
94. "What is said is believed supported and acted upon.
95. Transparency should be fundamental and children's lives and education should not be a chance or lottery but a priority "
96. Is there not an internal system where notes, information etc can be updated for all to view? A little like Patient Access in the NHS?
97. For everything to be 'joined up' and for all services to have access to the information that I provide - this would prevent me from having to repeat everything (or provide the written evidence) over and over again
98. Make it clearer to school staff that those teachers, TAs, etc working with a child with an EHCP need to have read the EHCP.
99. Update your IT and infrastructure
100. Talk to each other properly. Communication is key. Talk to parents and invite parents in.
101. People communicating with each other and doing what they say they are going to, when they say they will
102. Could not each child have an info sheet on them that professional need to read rather than at every meeting the parent carer having to tell the same story again.
103. Stop making children tick a box, they are individuals. Take the parents views on, not all of us have degrees, but we know our children. Finally open more specialist school up, clearly there are not enough spaces for the children who need them.
104. Effective communication between everyone involved, clear documentation providing set out plans. Being truthful
105. Read the file you'll know my child then
106. There needs to be someone who can act as an advocate for the EHCP child and their family. Someone who takes an actual interest in their story, and therefore understand their frustrations and stress. Support staff are great, teachers are overstretched and children are falling through the cracks. Hospitals have PALS as an independent arbitrator, but I'm unaware of any similar service for senar.
107. Understanding..... actually listen to us parents
108. Maybe person you're seeing actually reading your story before hand
109. Only to ask what they need to know not just for the sake of it"
110. Share information between department with a high turn over
111. Better communication is required

- 112. Consolidate all info. It's ridiculous seeing different doctors who have never met my child
- 113. No
- 114. Actual communication between services, not deferring responsibility to next service who then defer to next service and then again so on so on
- 115. Records need to be kept up to date. Staff turnover needs to be improved. The contact person (be that the SENAR WORKER or other staff such as travel assist) need to talk to each other and talk to parents.
- 116. We don't feel 'tell it once' has ever been successfully used eg. the long term absence of our case worker meant we had to tell our story every time we contacted SENAR as we got a different person each time who had no access to our case notes.
- 117. Create a passport style information pack for each child that starts from birth and is shared with the services when appropriate and can be accessed by the services prior to appointments and read. The passport can be added to by all services so everyone is in the loop.

## Appendix H –

### Q22 - What, if anything, do you think could be done to improve communications within the service?

- 1. Awareness, education and understanding
- 2. LA departments and external agencies need to stop working in silo's and communicate with each other
- 3. I had to share my lads EHCP with Birmingham Children's Hospital as BCC had failed to do it.
- 4. Actually start having communications in the first place
- 5. All attend meetings, no changing of staff frequently
- 6. An independent body whose sole job is to ensure the involved services communicate with each other and work together! Currently this is the parents' job.
- 7. Schools need to work more closely with Health providers. Third sector organisations such as SENDIASS have a vital role to play as third sector organisations, bridging the gap between professionals and parents and helping the ehcp process can run more smoothly. Other supporting not for profit organisations like All Saints youth project, Parks for Play can also support transition for young people with SEND.
- 8. Having records linked up properly, giving priority to children with such needs to access health services e.g. hearing tests, hospital appointments
- 9. Check that people are passing information on get an outside agency to do this
- 10. Have them all working together more often so they have a better relationship
- 11. More updates emails
- 12. Frequent area meetings?
- 13. Tin cans and a bit of string between the two or smoke signals would be an improvement right now.
- 14. For the health to turn up to the reviews
- 15. I don't know what you mean by 'the partnership'. What does this refer to?
- 16. Culture change work to instil in all staff the importance of quality and transparent communication and make ""No decision about me without me"". This is substantial work that's needed.
- 17. Council operational leads to support all-age neurodevelopmental pathway work.
- 18. My son has had the same paediatrician since he was 4 (statemented and EHCP since then too). He's 13 now and this year is the first time she has had her views accounted for because I've asked her to write them down. This is in spite of the fact that all of his school's new he had a paediatrician.
- 19. Keep more informed links about child and circumstances
- 20. Where do I start?
- 21. Be included in annual reviews if child has health issues
- 22. Health becoming more involved in the education sector. Once the child went to school the onus was on the school to contact services
- 23. I don't know but I feel that the way the system is set up is wrong. If a child has problems at school and a diagnosis, why should there be long delays. Why do parents have to fight for funding. It should be a given.
- 24. Listen to parents as well as professional as this is concerning the child
- 25. Database sharing system
- 26. Everyone involved in an EHCP should be given all the relevant information, so that everyone can attend the meetings which can, therefore, run smoothly and the child receives the necessary input from each of the education, health and care services.
- 27. Joint meetings with all involved to ascertain who is doing what.
- 28. closer working relationship in terms of supporting the child
- 29. Staff that are not on constant leave & you can actually get through to communicate with.
- 30. A centralised system for referrals so that staff can access support for families.
- 31. Effe drive monitoring
- 32. That they actually communicate with each other
- 33. It's not about communication - health and education are all in collusion together, neither understand SEN law or putting the reforms 2014 into action. They lack basic training
- 34. Senar staff could actually bother listening to others and actually turn up to reviews!!
- 35. The person who is supposed to manage my child's EHCP has never met my child, nor attended a single meeting or review.
- 36. They just see their job as saving LEA money from the demands of 'selfish, unreasonable' parents"
- 37. Don't feel well informed enough to answer this
- 38. Would know more about partnership as never heard of it and communication is poor between professional. To schools to carers feel like going round in circles
- 39. All services work in isolation and do their bit but are unaware of the big picture. Health and education in particular, support is given if it's physical need and not neurological need.
- 40. Make parents more aware about what activities there are out there for children with SEND
- 41. Health professionals sharing information more readily without reliance on parents passing information to schools.
- 42. More proactiveness would be good.
- 43. Services have become so tight they say they'll get back to you but never do"
- 44. Both my children's schools are very good at keeping the dialogue open with LA as they have experience of previous children's experiences being delayed
- 45. It would help if people actually turned up to the ehcp review meetings like they are supposed to rather than sending in an isolated letter with what they think
- 46. "Poor communication between services. More joined up working, health and social care very rarely contributing to EHCPs for example.
- 47. Gaining parental consent to share information on a community database that professionals within services can access.
- 48. Clarity on who does what

49. All partners attend meetings
50. Just open communication
51. Availability
52. Integrity in following the law and understanding of regulations
53. One single computer programme to link everyone involved with our child
54. They communicate?
55. As opposed to constant assessments of the child, have a single assessment process relevant to all agencies eg a pupil within my workplace has so far this half term been visited by an educational psychologist, a speech and language therapist and a SENDASS practitioner, all asking similar if not the same questions.
56. Don't lie to parents when they ask for help, like I did. I was lied to for years, and I'm disgusted with the system and people within it who lied to my child and myself!
57. "More communication between professionals is vital
58. Health did communicate. Education failed to keep all of the information.
59. Better communication with schools and principal officers and other professional can only happen if they actually all turn up to meeting when agreed and better written communication is needed. Have a back-up plan in case of long term sickness
60. Better team work better knowledge of the system more qualified staff
61. Listen to parents and carers. Organise meetings with the entire team of all necessary professionals there to listen and to discuss. Ensure things are written down, communicated clearly and followed up.
62. Health to talk to schools
63. Shared care record: electronic or parent held
64. School n GP should have more responsibility on that matter
65. MDT meetings. Professionals co-located. Systems that can be accessed by all.
66. Help
67. More communications
68. As with the previous question joined up working
69. Get rid of the I must save the council money mentality which obviously comes from above but doesn't allow the staff on the ground to do their job.
70. People are not answering their emails and phone calls and are not working full time so missing each other. I (mum) have had to try and coordinate services a lot. School and camhs not working well together has directly affected my child's health and care.
71. Professionals across the services must work as a team. Communicate effectively with each other and work together with best interest of the child at the Heart of Services.
72. One system where everyone logs comments and appointments. Maybe health attending ehcp reviews or even sending a report.
73. Communication between school and SENAR requires improvement in order to be completely effective. As a school we would offer help to SENAR in order to assist alleviate pressure of the service for the benefit of the children
74. There appears to be zero communication
75. Different agencies should work together - sly, ot, health, education
76. Health need to attend EHCP reviews and TAC meetings.
77. Communication is slow and this needs to be improved
78. Work together and act on what parent say and not just tick boxes
79. Integrated services
80. SENAR need to respond or reply to parents. When a principal officer is unavailable for a period of time someone else needs to take responsibility for their cases so things just don't stall.
81. Make communication system centralized so all sectors have access to same reports.
82. When medical/health need is dominant then plan should be led accordingly. Visa Verda
83. Services getting their facts correct in the first place so that incorrect information isn't cut and pasted from one document to another
84. Similar systems for sharing
85. A one point access that parents are also able to update to keep professionals informed
86. I don't know. My GP wasn't even aware.my son had autism 4 years after diagnosis. I had to provide the paperwork myself. And when there's a problem the go says it's the school doctors issue and vice versa. I get nowhere
87. More communication between professionals instead of parent playing middle man
88. Acknowledge and share information. Working together in the best interest of the child.
89. More funding and time for people to deliver critical services
90. Lots! I felt like I was left to it after his diagnosis
91. A complete change in approach.
92. Anything would be a start!
93. Open, honest and transparent shared process where the child is at the centre!!!!
94. Better communication with all parties.
95. I've never seen the input from anyone and have no sight of any advice sent by health professionals if they were asked for.
96. Social Care could actually send people to meetings when invited. Or at the very least send apologies of a report!
97. "Listen to believe
98. Integrity and transparency should be paramount and the journey of the child must be priority"
99. A more joined up approach. Not this is the paperwork our office needs but you need to do it all again for the next professional.
100. For them to actually talk to each other and share the information they have on my child
101. Direct communication. The only communication was information I provided health regarding education and information I provided to education regarding health. School didn't invite health professionals to the EHCP review, or even ask for a report or information.
102. Shared databases
103. Email, ring send letters to communicate, if this is being done and as with all communication issues, then when it's not carried out as it should be the members of staff should be reprimanded properly along the council guidelines between employers and employees. These are children not items. People need to be made accountable when things go wrong. At the moment people get away with things because they know they can. No one's job is irreplaceable.
104. More staff to deliver the service, for diagnosis for children to be easier, for parents to be supported at one of the most emotional times of their lives. For understanding for everyone involved.
105. I seem to pass information more quickly than they do.
106. Anything would be better, nil happening at all at the moment.
107. Better communication between Heath, social services and education rather than all working independently.
108. People returning calls and emails.
109. I play go between for my child. I report to his doctor about what school have said and his versa.

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| <p>110. They need to realise that the child should come before all else and parents needs constant communication updates regardless of cost</p> <p>111. Despite having the same paediatrician for 8 years, she has never been contacted for her views despite me asking in multiple occasions. She has now written a letter for his EHCP review as she is also frustrated at the lack of input. Unfortunately the EHCP review has been continuously put off since March!</p> <p>112. Keep files up to date and communication... read the child's case before engaging into conversation ... meeting the family to get better insight must be a positive ... meeting the child is beneficial as you're not just reading reports</p> <p>113. Trained staff that communicate properly</p> <p>114. Maybe to have one place to access information</p> <p>115. Making sur information is ultimately up to date so when and if it is shared you get the correct details</p> <p>116. Better communication</p> <p>117. a document that can be updates and gives all information like a hospital passport</p> | <p>118. Again consolidate all info showing live up to date info</p> <p>119. They communicate with each other more. Time and resources need upping</p> <p>120. Actual communication, I can't see any at the moment!</p> <p>121. The school does not have good links with SENAR. SENAR does not have good links with travel assist. Other support services such as SALT or Ed Pysch are not funded adequately to provide the advice and guidance that is need so reports are often late delaying the process. No one talks to health professionals such as CAMHS. Through all interactions with LA SEND services there is a clear lack of communication and no acknowledge that this needs to be improved. The impact of this is that children are left with inadequate or no provision for long periods of time which is very damaging to not only their ability to learn but more importantly their ability to become well rounded adults who are able to function successfully in society.</p> <p>122. Contact points and information to assist in developing support projects</p> <p>123. Talking and listening to each other quite simple really!</p> |
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## Appendix I

Q30 – Parents were asked to select one of three options for support that could be offered whilst waiting for therapy appointments - Online services, telephone helpline or other. If other, please give examples.

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| <p>1. charitable services with specific knowledge of my child's condition</p> <p>2. Just letters to acknowledge we were still on the waiting list, and moving up the list.</p> <p>3. Regularly email to see if help was needed</p> <p>4. A helpline and support group for parents to go and talk about concerns</p> <p>5. A person .not a website but a human been</p> <p>6. Better communication</p> <p>7. Both online and telephone</p> <p>8. Alternative therapies advised, alternative resources highlighted.</p> <p>9. None, if the child needs therapy, they need therapy. Online or phone support is just gatekeeping to manage demand and has no benefit for the child</p> <p>10. anything, just to know I was still on the system</p> <p>11. Updates on what's happening regarding the referral&amp; updates on where on waiting list we are</p> <p>12. We waited for psychological input - appointment date was 6 months after referral and child went into crisis before appointment came.</p> <p>13. My son was discharge from CAMHS because funding was "no longer available" for anger management via CAMHS OT. This didn't mean the need was no longer there and that he no longer requires help.</p> <p>14. Consultation with someone</p> <p>15. Support groups or workshops with practical advice or techniques or strategies to be used</p> <p>16. An idea of how long we will be waiting for, some tips of things to try whilst waiting, a group session to explain what speech is normal for our child's age and tips</p> <p>17. reduced waiting times</p> <p>18. An actual appointment!! My child is currently still waiting after 4 years. Neither the LEA or the NHS are willing to take responsibility for arranging his Speech therapy</p> <p>19. We have used speech therapy over the years but it was a long time ago, can't remember waiting times . It was poor at times due to lack of funding and staffing problems</p> <p>20. Letters. As parents can be too busy to open up their emails account and may miss something.</p> <p>21. LA support</p> <p>22. Just letting you know you haven't been forgotten about</p> <p>23. Someone always there to talk to</p> | <p>24. Casework support from someone who understands SEND law</p> <p>25. I do not know what types of support or available. I know what is available in Solihull that I cannot access but not in Birmingham which I also cannot access.</p> <p>26. An app would be good for SALT. A letter following up assessment from OT would be good. Referred three times, waited two years for assessment. Assessment completed, no letter received. Followed by dyspraxia assessment and again no follow up letter received</p> <p>27. Just being kept up to date would of help</p> <p>28. People actually doing the job we pay out taxes for.</p> <p>29. Quicker waiting lists, people who answer the phones.</p> <p>30. Ok</p> <p>31. Face to face visit</p> <p>32. Interim plan, supporting School, home, individual</p> <p>33. Re speech and language therapy, we ended up paying an independent therapist to assess our daughter because SENAR forgot to request an assessment as instructed by the refusal to assess tribunal and then didn't have enough time to get an appointment before the deadline for providing evidence for the EHC needs assessment</p> <p>34. Online /live chat or drop in clinics</p> <p>35. Communication</p> <p>36. Both online and telephone</p> <p>37. Knowledgeable accessible support groups</p> <p>38. A community hub or centre to access a person to help parents and families hard to reach</p> <p>39. A key professional within health to oversee child's care as that should have been consultant paediatrician but we only see her once a year</p> <p>40. Letters, emails and phone calls and people sticking to statutory guidelines and timeframes and also to their word</p> <p>41. Support groups</p> <p>42. To be told how long the waiting list was rather than the markers keep on changing</p> <p>43. Constant communication</p> <p>44. No communication it is left down to parents to chase</p> <p>45. Facebook groups</p> <p>46. Letters info confirmation it is booked</p> <p>47. Support worker to contact.</p> <p>48. SEND services do not refer to additional support often. A school may but this is based on what budget is available</p> |
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for the school which is often a lot less than what is needed. An example of this was a mainstream secondary with a ASC resource base. The school has only paid for 10 hrs Ed Psycj support for a full academic year even though an assessment and report takes 3/4 hrs to complete. This

meant that even though the resource base had 30 pupils plus a lot of other pupils in full mainstream, they were only able to offer 1 hour for 10 pupils. The main issue with this is that there is no formal way of complaining about these kinds of issues and there is no accountability.

## Appendix J

Q33 - Parent / Carers where asked if they had visited the local offer website and if yes what simple things would you do to improve it?

1. All third sector support charities are not listed which I have relied on for support when no statutory services were available
2. Does not really give any practical information
3. It is not updated as far as schools.
4. Easier to navigate system
5. Make it more user friendly. It's very difficult to navigate at present.
6. Make sure what is offered is delivered, provide information on actual access to and outcomes of services listed
7. Make it easier to negotiate around and be more user friendly and actually be of relevance
8. The layout so it's easier to navigate through
9. Make it clearer & easier to find information
10. Make information factual
11. Too hard to navigate
12. Make links work.
13. Make it easier to navigate.
14. Co-produced information.
15. Make it clear and to the point. What are we eligible for and what aren't we eligible for - simple as that.
16. Instructions on how to navigate the website. Have a website that is simpler to navigate. Add more information especially around different educational provisions in Birmingham rather than links that only give an address for the provision.
17. Very confusing if you're a first time on the website
18. The local offer is out of date and it is unclear who completes the updates. It is not well publicised.
19. Sign posting to areas that are of actual use to provide the support that is required
20. Never heard of it
21. More simplified & information not always up to date.
22. It's useless. Start again from scratch it only links with senar and education.
23. It should be clearer, more concise. Information is not accessible and parents find it hard to navigate. Poor IT is the cause and information is outdated.
24. Shorter.
25. Clear language
26. Outline the LEAs legal responsibility
27. Know about the partnership so. I can know about the services and seek help
28. It's very superficial, possibly needs examples of specific support.
29. Easier pathways through the links.
30. "More clarity, it is difficult for parents to find what they are looking for. Needs to be more user friendly. Parents are unclear as to its purpose.
31. More detailed information, it is currently very basic."
32. Accurately follow the requirements as laid out by the Council for Disabled Children
33. Easier to understand interface and the ability for it to get us the correct info we are after without searching different areas multiple times
34. Ensure better signposting by schools etc.
35. Proper information that is helpful, with links that work
36. Better signposting areas on the website
37. Not necessarily the site, but the offers are so tokenistic. I cannot wait until a certain time on a certain day to go places, and events such as autism friendly hour in a supermarket is useless if the child is at school or at an autism friendly cinema screening at that time!
38. Make it more reader friendly and clearer menus
39. Make people aware of it
40. Whoever dealing with this Stop ignoring that matter, please put importance on that.
41. Easier to navigate. Straightforward language. Videos explains rather than pages of text. Shouldn't need to search out what the 'offer' is if you are engaged with the system & clearly communicated with at each stage of processes in the first place.
42. more in depth information
43. The web site is quite hard to navigate
44. More in depth information and sign posting of all the services that are available across Birmingham
45. Improve information about processes and support so that there isn't such a negative slant based on the fact that services are so stretched - written information and advice
46. Join up your thinking. Tell the truth. What u say is happening is not happening!
47. Easier to navigate for parents including practical advice e.g. when is quiet hour at Asda / Tesco etc? Is there a parent course running for physio needs?
48. Easier to navigate - clearer information, more easily searchable
49. To be easier to find
50. Up to date information
51. Specific details for SEND not just generic children's provision"
52. Make the website easier to find and to access.
53. Interactive in terms of school logistics from home, support expertise/champion at each school
54. Better information
55. Clearer information that can be easier understood
56. Unsure as not used it
57. Redesign as it didn't really give clear information, a lot was out of date and confusing.
58. Make it easier to navigate
59. Needs to be easier to access and understand
60. Make it clearer to understand. The phrases used are confusion and not clear. Too bureaucratic. What does local offer mean???
61. Links to external sources of information from children's disability chary (such as Mencap and Contact) rather than the insistence on branding everything with a "Birmingham Brush". There is plenty of excellent information out there, why try to reinvent everything?
62. "Signpost to signpost is not effective communication
63. Clear languages and pictures to explain services page by page "
64. Not having 'dead' links and not having to click on various links before being able to find the answer to my questions
65. Have sections indicating what everyone could access, what you would need funding to access, what you would need a referral to access.

66. Change it. Is difficult to navigate. Have no idea where to start so I pity those who are computer clueless.
67. Give the information instead of telling people to download the documents. Not all people know how to use a PC
68. Make sure it is updated. Preference forms were late being added to website. When phoned kept being told it was a printer issue, really. The preference form doesn't change, only the date and this can be written in.
69. Make it easier to navigate and have up to date info on it
70. Signpost clear, some answers I couldn't find when indeed of support.
71. Be clear, I have wasted hours trying to go through all different websites trying to find support for my child.
72. Up to date info
73. It needs to be much clearer and more concise regarding what is available and how to apply. Very vague.
74. Simplify
75. Clear consistent information
76. I have no experience of using this. Even this survey does not make sense and needed more time put into it as these last two questions are irrelevant and I can't skip them.
77. Not to crash, to actually present what is available not a vague idea of what you may ask for but actually there is no funding for.
78. Is it difficult to navigate, make it a lot simpler. Ensure information is up to date, easy to find and is relevant.
79. Improve navigation around the site.
80. The site map and home page are very unappealing and complicated for a parent. These pages should be more friendly to someone not trained in special needs

## Appendix K

Q36 - What would have improved your experience into transitions? Please give examples.

1. Transition from school to college needs SENAR to attend, social services don't return calls not good enough
2. More out there for older
3. My daughter is currently transferring into adult services - don't understand why it takes so long?
4. She turned 18 in April. "
5. Seamless transition from children's to adults - supported hand over from one key worker/ named person to another.
6. Access to adults OT as ASD not diagnosed until 23 no OT service available for help with sensory difficulties "
7. More information and awareness needs to be given. We had no awareness of what benefits my daughter could receive as an adult. If I hadn't been around to provide for my daughter I dread to think what would happen to her. I am now pursuing what she may be entitled to but again had no idea of what she could receive.
8. If services as outlined within his package were ready to commence immediately at the new placement as it has already been identified the support that is needed.
9. Joined up working
10. More support and help
11. We waited over a year for appointments from child to adult services
12. Better transition, more information, more services to access!
13. Effective Post 19 process in SENAR that understands the regulations
14. Support, guidance. Not dismissing the child and their needs because it's more mental than physical. Listening to carers. Not being rejected for PIP when it is clear there is a diagnosed need for it. Being supported when local college rejected the student when they couldn't meet his needs.
15. The authority need you pay more attention on that matter.
16. More resources for 16+
17. Everything hence my complaint to LGO
18. I am dreading this. I am told that adult services are horrific. It's all about money and not spending it
19. Improved Communication.
20. I've not experienced this as a parent yet
21. I am an autistic adult, I was diagnosed at 30. I have been offered NOTHING by way of support. Nothing at all. I don't receive benefits for me or my son, for example. Help applying for benefits as standard after diagnosis would be helpful. Support groups. Therapy. Just something?! It is very lonely and isolating. I received my diagnosis at a time when my mental health was appalling and my son's behaviour was very challenging and we were given nothing. I had no treatment from the NHS for my mental health. Had I been treated, I would have been able to support his needs better, improving his behaviour. He has suffered as a result of this. He has been let down. And me, and my husband, and our other child. It has impacted us all negatively.
22. Communication between children's and adult services - contact names to be provided
23. Information being available much earlier to ease anxiety. Transition information should be available from Y9, but in reality there seemed to be a veil of secrecy over what to expect until my son was nearly 18
24. CAMHS! Need to stop discharging just because they aren't threatening own life
25. Communication.... my daughter is 24 and had no help what so ever since she left school
26. Anything more services
27. Better communication is required
28. Again no experience should have skipped this question
29. Start earlier than 18, understand that bombarding someone with Id and processing difficulties will lead to shut down and non-engagement. Not focus on what you want to offer but what that person needs.