

Appendix 4: Interview session notes from meeting with parents

Questions for Parents & Families

Stakeholder Specific Questions

- a) What is your understanding of speech and language development for your child, and why its important?
- b) Would you be prepared to be interviewed as a case study?
- c) What are your experiences in lockdown?
- d) What are you most worried about?
- e) What do you know now which you wish you'd known before?
- f) Are there any resources you wish you had more access to?
- g) What do you think nurseries are doing already and what do you want more of?
- h) Have you heard of the Camden Welcome Programme?
- i) Have you been able to access speech therapy, if you thought your child needed it?

Cllr McNamara Interviews with Parents

I met with parents of children attending the nursery at the Regent's Park Children's Centre, Augustus Street, NW1 3TJ on Wednesday 23rd November. The participation manager had contacted a number of parents to encourage them to come and talk about their children's language development. It was an extremely wet morning and only six of the expected fifteen parents came. As you can see from the notes below, four of the six of the parents' children had a diagnosis: Autistic Spectrum Disorder- ASD/autism/. The other two were Farsi speaking at home and didn't speak nearly as much as the other four mothers, but they were equally concerned about the lack of language, given the age of their children.

Mother A - Black woman, Camden born and educated 6-year-old daughter child at St Dominic's- school is closing, trying to get her into another school and to get an EHCP (Education Health Care Plan)

Mother B – Spanish, her job is a Nanny ,has worked as such for over 10 years in this country – first child didn't develop language or make eye contact- now has a second child – she does exactly the same with this child and this one responds well and develops easily- took her first child back to Spain recently, got an autism diagnosis and paid privately for therapy as didn't get heard by Health Services here

Mother C - was living in Essex, both she and her husband are paramedics, have one male child, didn't develop language - GP helped her get him into Nursery at Regent's Park CC and he got an autism diagnosis.

Mother D - Polish- one male child – didn't develop language or play - took him back to Poland when he was sixteen months for 6 months, when she lived with her mother- partner very unhappy as he couldn't see him but her son had all therapies- got an assessment and autism diagnosis -speech therapy- physical therapy- neurologist.

Mother E - Farsi speaker, has daughter 4 years old, goes to school, doesn't speak in either English or Farsi, very shy, covers her mouth and doesn't speak. No help offered?

Mother F - Farsi speaker has 2-year-old – friend has 2 children and they used to meet but her child doesn't interact and doesn't speak- although now talking is getting better.

Stakeholder Specific Questions

a) What is your understanding of speech and language development for your child and why is it important? Q C) What are your experiences in lockdown?

This was my opener question, and the replies were basically a description of their situation, the replies covered the experiences in lockdown as well so I didn't revisit this.

Mother A - We are still waiting for proper support, speech and language no support, when my child was 3 years old we knew he needed it but nothing, then Covid struck – I have two other children

Here for 3 days a week, Stay and Play, 1 other child

Clapping, waving, using Makaton- understands more than he says

6 years old ASD 2019 needed speech and language therapy, got a referral to Mosaic - took 6 months to get that referral and only just got a diagnosis this year.

At the Nursery in the Harwood Centre no school for one and a half years because of Covid- child stopped talking in the house- too confined, too little space- used to walk up and down up and down the living room – pacing.

I am a Nanny, so I took my child to work and at least he had the other child I look after to play with - at one year old didn't look like the usual line of development and I knew what that was because of my job, Doctors and Health Visitors didn't validate her.

There was no eye contact at all- nothing happening he was not developing then my daughter she was born- 1 went to Spain and got speech and language support there – came back and was supported by the Nursery here and got referral to Mosaic, now verbal can speak, but social skills just not there.

My son doesn't play with toys- learns by watching other children- now eats spaghetti and eats with a knife and fork- never did that at home, only since coming to nursery. Did loads of stuff with him, but there were no other children- he was surrounded by adults, no other children. We had illegal playdates - we were all going crazy and knew our children needed other children, so we went to other friends' gardens or walked in the wood- even tried to buy a log cabin but they couldn't do it. People were scared, they wouldn't help you - especially with me being a paramedic- I fell over in uniform and no one came to help pick me- up they just stood back and asked if I was ok. I knew people who were not scared, and they just wanted to get together outside with children. Remember playgrounds were closed for over a year.

Also, if Covid hadn't happened we wouldn't have known what was wrong. My daughter is four years old and doesn't speak fluently at all - just says words not sentences- during Covid couldn't get help- there was no point of reference to help us - the on line assessment zoom assessments were ridiculous.

At 16 months I went back to Poland and stayed there for 6 months. I had face-to-face physiotherapy- we all wore masks but we were actually in the room together, and had Occupational Therapy and speech and language support, and we saw a neurologist - the amount of investigation and help was great. It was still Covid, but they still saw me - but the whole charade cost me my job and had a negative impact on my husband, as he couldn't visit until January this year. In the nursery here, yes, I can see progress now and I could see progress in Poland.

With the Covid Pandemic there was no early intervention – got it now, but it doesn't make any sense, it costs more money because the problems are now more severe. Up to 4 years old the brain is very plastic and can develop and change if you intervene, after that it's so hard.

With Covid there was a lack of resources for children but also a lack of support for parents- so what were they doing? The health visitors would call you for a check-up 'Zoom call'- is he talking yet? But no actual help and advice on what to do to get him talking - for special needs kids I don't have the skills. I am a nanny I didn't know what to do if the development wasn't usual- I didn't know how to connect with him so I went to Spain and paid privately.

My baby was born in lockdown and is very shy. My friend has 2 children but she doesn't talk, plays without talking, now getting a bit better- is 2 years old

b) Would you be prepared to be interviewed as a case study?

Yes, I have contact details for five of them

c) What are you most worried about?

Guilt – at this point the mother became very distressed- we survived but we were both working and we had meetings on line so I gave him a tablet to play with in his cot and I knew I shouldn't be doing that, but I had to because we had meetings and I felt so guilty- people lost jobs I didn't, but then I was so worried I chose to give up my job and go back to Poland. But I feel maybe I damaged my child – I was a new mum and breast feeding and constantly worried – I feel so much guilt and so sad that I couldn't support my baby properly.

Transitions is what I am most concerned about, they have a huge impact for ASD children they don't settle straight away - and my child screams. She is at Primary School and gets one-to-one help. I strongly recommend all of you to get an EHCP here at Nursery because it is different if they come up with a plan. It takes 3 months 20 weeks to get an assessment and then it took us three years- 2019-2022 to get approval- it takes so long to prove that your child has difficulties.

Yes, I am worried about M... transitioning from the nursery to choosing the right school- I have had conversations with Netley and Christchurch. Here you can talk to anyone, but schools are not so welcoming – here they know you and your child on a daily basis – choosing a school is my biggest worry.

You should go to schools during the day, we did, and I asked the headteacher what do you do if a child asks you for a cuddle and he said it depends on the child, and right then a child came hugged his legs and he hugged him back! Also ask them if they will do potty training – one said yes, one said no!

d) What do you know now which you wish you'd known before?

Education for us as adults around signs of delay.

A brochure on what you can expect and information to look up if your child doesn't do it- a try this approach- Videos so you can see what development usually looks like.

I look at videos of M now and I can see he wasn't looking into anyone's eyes. I could see when we had a playdate illegally that he wasn't interacting with the others, just playing alone- and he looked scared and terrified.

I wish I had known more about how children develop - it was very stressful- when you have a child with difficulties, and there is no help. It affects your own mental health.

People were just not seeing anyone- why not get a phone call? Why didn't they phone? Health Visitors could have taken a list of Camden parents and once a month each one takes a batch and phones them to support families and parents.

e) Are there any resources you wish you had more access to?

See answers above – they couldn't access anything useful

f) What do you think nurseries are doing already and what do you want more of?

Nurseries – and I know this is very difficult because of funding but nurseries should have someone with an awareness of children with difficulties - you know I have awareness now - it I see a child with difficulties I can straight away see that child needs help, because I have been through a lot with my son. So, someone with awareness in the Nursery sector they should detect that and identify that they need to be sent to a professional and to be assessed. I don't mean to say they should be on this level or that level, but just to detect difficulties.

Nursery for me has been a life saver. I didn't know what was available here - maybe because I am not from here, but Spain. But since he has been here and he has been a bit delayed from going to speech therapy, but now the nursery has helped to get that appointment and we are being assessed by Mosaic. But I do think it was very unfair, because we don't qualify for the two-year-old funding, and we had to wait for the three-year-old funding. We couldn't afford a place at nursery when he was two, even though we are both working, so I feel like we lost such a precious time when he was two and needed support. At Nursery they have shown me a path and finally I feel like we will get the help that is available, whereas before all I knew was the Health Visitor and GP, and they kept saying he is too young, and every child is different, and they develop at different rates, and I knew I knew from being a nanny

and a mother this was different. I was so frustrated and finally Nursery has opened the way for me. I wish he had had a two-year-old place - because now he is going to be four in January. Now I am looking for a school to start Reception next year. I know him very well, but I don't where he will learn better- we still haven't got a proper diagnosis and time is ticking, so I wish we knew. Even if a child doesn't go to Nursery, it should be able to refer me – I was lucky I went back to Spain.

I can't fault Nursery but it does seem a bit frustrating. Obviously I have got nothing against people who can't work, or single parents etc etc, but basically me and my husband both work. He is full time and I am part-time but we get penalised for that and our child can't go to Nursery until he is two.

Should Nursery be available free for everybody?

Yes from two definitely, because we don't know what to do to help them develop, child care is different but I had to wait till E was three and that's a lot of years gone, I don't know what I am doing. Most of the parents who don't work aren't sending their children to Nursery so they can work, they are sending them there for the child's own development. I didn't want E to come to Nursery first I time- I broke down in tears- they said he needs to, and I said but why- but he is a changed child now, he runs in now- it's about him it's what he requires.

He was always going to be autistic, I get that- but another extra year to have all that input would have made a huge difference and surely the sensible thing is – get in there early and help them, and then all this funding that they need in the schools later on, because they have been misdiagnosed etc, wouldn't be happening. It's just crazy that – put it in there early and you won't need it later on because the hard work has already been done.

We still do stuff- we go to the park and make playdough after Nursery. I felt guilty putting child in Nursery – but when she came along (second child) to lift the guilt I thought, oh yes, he has needs if I had come to nursery earlier it would already have been a better path - he came in June and in November he is just settled - transition takes longer - I am scared for the next transition.

We are not using Nursery for child care- we are using it for our child to get help to develop now.

Also, in Covid parents couldn't go into the class to help their child settle - now I can go with my child into the class.

g) Have you heard of the Camden Wellcom Programme?

Yes – it's a shame the resources weren't there before.

But we have to remember so much good came out of Covid- we are alive, we have got jobs, and our children are safe

h) Have you been able to access speech therapy if you thought your child needed it?

No!

Any other questions?

Why is three, the cut off point for extra support in Nursery why isn't it two - two-year-olds can talk?

We had the two-year-old review on a Zoom call - they said why are you giving your child a bottle? why does he have a dummy he is two? - so judgemental- that's why he is not talking. I said, No, that's not true- he isn't waving, he isn't communicating at all, at 18 months no clapping. GP in Essex was awful- I told him. At seven months. I came to Camden- changed to the James Wigg Practice, in just over 6 months everything was sorted out .

The Health Visitor wasn't listening to me, GP not listening, had to go Spain.

Give me some tools.

Amazing what this Nursery has done with him- I want them to build a school on this site!!

I have done research with other Boroughs and actually Camden has the best provision for Special Needs.

No, just so grateful – thank you for listening - I haven't spoken about this to anyone else.

They were there for approx. 90 minutes!