**Parent Interview6**

**Date: 13 Dec 2022**

**Duration: 0:27:22**

Interviewer: Preamble

I just wondered if you could say anything generally about what you think about what it’s like for people living on a low income at the minute.

Parent6 With myself you’ve got low income and you’ve got a child with disability, so lack of understanding as well. We have to access the GP probably a little bit more than other parents. You’re having to ring 30 to 90 times to get through, so maybe making GP numbers a freephone number.

Interviewer: That’s an interesting thought. I hadn’t even thought about that, but obviously there’s a cost associated with every call.

Parent6 Personally, my GP do not accept walk-ins anymore, you have to ring up.

Interviewer: Do you mean you’re having to phone multiple, 30-plus times?

Parent6 I think the record is 124 to get an appointment one morning.

Interviewer: Crikey. That’s an awful time commitment as well as anything else, isn’t it?

Parent6 I know they don’t charge you until you’re put through, but that could still be daunting if you didn’t understand that they don’t charge you until you’re put through.

Interviewer: That’s a really interesting point, I hadn’t even thought of it. Yes, that is really interesting. Can you tell me a bit about your experiences of accessing healthcare?

Parent6 Diabolical.

Interviewer: That’s a barrier if you have to phone that many times.

Parent6 Diabolical.

Interviewer: In what way would you say? Is that about your GP or more widely than just GP?

Parent6 It’s really just the GP. My health visitors, if you can’t get her we’ve got a number for the office. The consultant’s secretary, but I think at the minute that’s heavily COVID based with sickness.

Interviewer: You mean lack of service because of sickness.

Parent6 Yes, what’s out of the control for the consultants.

Interviewer: Normally, non-COVID times, is that a way of getting access to services through that?

Parent6 Ring the secretaries, yes.

Interviewer: That’s for the hospital consultant you mean, do you?

Parent6 Yes.

Interviewer: Is that something you’ve done in the past?

Parent6 Many a time.

Interviewer: Is that boycotting the GP then?

Parent6 It’s more that the GPs half the time say, “We haven’t got any idea on Down’s Syndrome, ring the consultant, the paediatrician.” It’s a lack of experience. I know they’ve got at least three children because I’m an ex-youth worker. I know of those families, but I can’t say, as you’ll understand.

Interviewer: They’re registered with your GP you mean.

Parent6 Yes, there are at least three. They can’t comment on the condition.

Interviewer: They would direct you to go to the consultant rather than…

Parent6 They say, “Ring the health visitor.” Then the health visitor says, “Ring the consultant.” You feel like a parcel in the pass the parcel.

Interviewer: Very frustrating. What’s the next step if you manage to get through via the secretary or by some way to a consultant, are you then offered an appointment to go?

Parent6 It depends what it is. If it’s just a slight change of medication or something, we sort it out over email. There are only three paediatric consultants in Northumberland for all the kids.

Interviewer: For all the children, that’s not a great ratio, is it, of consultants to children.

Parent6 If we can sort it out or get the plan to the next review, we’ll do it that way.

Interviewer: If you did need to go for an in-person consultation, how does that work? Where do you have to get to?

Parent6 We have to go to [hospital name]. Luckily, I’ve got a free bus pass because I’ve got disabilities myself. If I didn’t have a free bus pass, it would be £5 for a single fare or £6.50 to £9.00 for a return.

Interviewer: If you needed to pay that would be quite a substantial outlay then just to go to the hospital.

Parent6 It would be classed as a two zone [bus company] ticket for us for the hospital. If you have to go to [another hodpital], that’s the main hospital for us [ \_\_\_0:07:15], it could be up to four buses there and back.

Interviewer: It’s not just the cost, it’s also difficult just managing it when you’ve got the pram and everything on and off the bus.

Parent6 When you’ve got the pram, if there’s one person with a pram and a wheelchair you can’t get on that bus.

Interviewer: You have to wait. That’s a real access issue, isn’t it?

Parent6 Can I go on about drivers and companies?

Interviewer: You can, anything. We’re very interested in anything.

Parent6 The bus companies don’t understand that child is older, get the child out the pram. Prams these days don’t collapse. I’ve got a Silver Cross and it takes up more room collapsed.

Interviewer: It’s not even that you could fold it and make way for everybody.

Parent6 Because of her Down’s Syndrome we’re recommended not to use a buggy for long spaces of time because we’ve got her bottles, we’ve got her food, we’ve got her inhalers. We’ve got potential medication on us whether it be fridge, so that’s an ice-cube bag.

Interviewer: You’ve got a lot of equipment.

Parent6 Not including normal baby stuff.

Interviewer: I remember when mine were little there was enough stuff to take without any special equipment.

Parent6 One of my friends has to have oxygen and the amount of drivers decline them on the bus because they were a smoker.

Interviewer: That’s unbelievable, I’m surprised they would be allowed to. Maybe they’re not really supposed to.

Parent6 I don’t know if they are or not supposed to. Just put your lighter somewhere safe and lock the lighter.

Interviewer: Yes, exactly. We’re thinking if you’re on a low income. I suppose what you’re saying is if you didn’t have your bus pass, would that act as a barrier to you going to the hospital?

Parent6 You would have to plan and potentially go without.

Interviewer: Is there potential for online, so this sort of Zoom type?

Parent6 It’s either telephone or in person. They don’t offer video very easily, even though the doctors are well-equipped to set up for video.

Interviewer: They’re not keen to do that. I thought maybe during the pandemic had it become more common, but I don’t really know.

Parent6 My surgery not everyone is doing it, not everyone is comfortable with it. If you’re on a low income, do you have the technology to do it?

Interviewer: That was going to be my next question. I think that is a problem for people.

Parent6 I’ve got an iPad on finance from my dad.

Interviewer: Is that how you’re doing this today?

Parent6 Yes.

Interviewer: You’re right, it is difficult for people.

Parent6 Not everybody on a low income has a phone.

Interviewer: No, exactly. That’s a really good point. That’s a whole issue around just getting the appointment in the first place if you’re having to make 30-plus phone calls.

Parent6 I’ve worked with children. I was a young leader when I was 14 in Girl Guiding, so I’ve seen it as a leader as well with families. There was one family that had to either decide if they were going to have heating on or have a shower.

Interviewer: Because they were making decisions based on the cost of the energy to provide the hot water.

Parent6 Basically, yes.

Interviewer: A horrible position to be in, isn’t it? Thinking about the healthcare, if you do attend the hospital if you go up to [hospital name] and I know you can get there on your bus pass. Then what about when you’re there, are there costs associated with being there that you wouldn’t have?

Parent6 It depends what the delay is.

Interviewer: Often people have said…

Parent6 It depends if you’ve got multiple appointments on the one day.

Interviewer: You might need to buy food, for example, when you’re there. Is that something you’ve experienced.

Parent6 Sometimes, “We’ve got a two-hour delay.” I’ve got an eight-month-old child. It was a four-and-a-half-month-old child at that point. At that point in the pandemic we were using the baby changing room and the baby changing room was a store cupboard.

Interviewer: They didn’t even have a proper baby changing room.

Parent6 They did have one the other side of the hospital.

Interviewer: But not convenient for you.

Parent6 I was actually waiting to be seen myself.

Interviewer: This was for you rather than for your daughter.

Parent6 I had to take the baby with me because my partner is not on the scene.

Interviewer: Is that an issue for you if you need to see anybody, GP or…?

Parent6 With the pandemic they’re saying, “Please attend alone, please don’t even bring your child.”

Interviewer: If you’ve no one to leave her with, then I guess…

Parent6 I’ve had to either say it’s me attending with my child or me not attending.

Interviewer: That’s the choice you’re making.

Parent6 What we’ve agreed with me, we’ll do one in person and one on the telephone, one in person and one on the telephone.

Interviewer: That’s with your GP.

Parent6 The hospital, respiratory.

Interviewer: Is that working okay for you then, are there any issues?

Parent6 It’s not the best because respiratory you really need to be seen in person.

Interviewer: Yes, difficult.

Parent6 I know they do the free transport, but you have to be ready two hours before and you could be waiting up to two hours after.

Interviewer: Which is bad enough for you, but when you’ve got a young child as well.

Parent6 If you’ve got a pram, they won’t do it.

Interviewer: Will they not let you take the pram?

Parent6 They won’t do it with a pram.

Interviewer: You have to take the bus in that case.

Parent6 Yes.

Interviewer: What about the timing of those appointments, is that convenient for you? Are you able to attend appointments?

Parent6 It’s hard because [ \_\_\_0:13:01] social services plan and we have to attend two groups a month. Because of my ex-partner attacking us when I was in hospital, she’s on a child protection plan.

Interviewer: Oh dear, I’m sorry to hear that.

Parent6 I’ve told the hospital and they did nothing to nip it in the bud. I was asking them for help.

Interviewer: And they didn’t. Is he out of the picture now completely?

Parent6 He’s banned by the police and social services.

Interviewer: A commitment for you is attending those meetings with social services.

Parent6 That, my two groups I attend each week, one being disability and one being through church.

Interviewer: You need to fit in around those.

Parent6 What I say is hospital appointments come first, but they’re not always that easy to change. A lot of them are, “We just do an afternoon clinic once a month.”

Interviewer: There’s no flexibility.

Parent6 Or you have to go to this hospital 16 miles down the road.

Interviewer: Do you think there would be better ways they could schedule those? Would you prefer more flexibility?

Parent6 Maybe do one afternoon and one morning.

Interviewer: Give a bit more choice. What about if they did different days, weekend days or would that not be an issue for you?

Parent6 Weekend days wouldn’t be a bother for me, but I don’t work.

Interviewer: For somebody that was working it might be more of a difficulty if they need to get…

Parent6 Or have children in education who a child needs the appointments for. If the child is in a poverty bit, they’re more likely to be behind at school, so you don’t want to be taking them out of school to fall more behind.

Interviewer: That’s a really good point. Yes, absolutely. Do you have any other children?

Parent6 No, just [child name].

Interviewer: [child name]. I was trying to remember her name, [child name]. Is she alright? I can hear her.

Parent6 Yes. She’s just lost her teether. I’ve unclipped it because it’s pulling the babygrow down. She’s only had them a week and they’ve got too small.

Interviewer: Oh no, is she growing fast?

Parent6 She was only born 4lbs 6oz, but she’s now I’d say at least 16lbs 8oz. She was 16lbs 2oz before Christmas.

Interviewer: She’s four times the size.

Parent6 Yes.

Interviewer: You must be always buying new babygrows then.

Parent6 I buy second hand a lot of the time [ \_\_\_0:15:30].

Interviewer: I think it’s the right thing to do anyway for the environment.

Parent6 For example, for a packet of three babygrows, if you can get the white they’re £5.50. if you can’t, they go up to £9.

Interviewer: Is that if they’re coloured or they’ve got a pattern?

Parent6 If they’ve got a pattern on, they go to £9.

Interviewer: It makes them more expensive.

Parent6 If they haven’t got them, they go up again.

Interviewer: If you can get them second hand you might as well.

Parent6 I get bundles on Facebook.

Interviewer: They wear them for such a short time, don’t they, and then they’re out of them.

Parent6 I’m very lucky because my friends have all got older girls.

Interviewer: You’re able to inherit, that’s handy.

Parent6 Yes. With the healthcare side of things, you never know… If you ask about the transport they can be quite shifty with you, especially if you’re young.

Interviewer: Why do you think that is?

Parent6 We need to keep it for the older generation, as I’ve been told once.

Interviewer: Oh really, they feel like you should be able to manage under your own steam.

Parent6 Sometimes the older ones on a pension get more than some of them on benefits.

Interviewer: Yes, that’s true. Was [child name] diagnosed when she was born?

Parent6 Yes.

Interviewer: Has that meant a lot of hospital appointments, more than you would have…?

Parent6 We’ve had speech therapy that we’re waiting for at the minute. Sight, hearing and oxygen [ \_\_\_0:17:19]. One’s [hospital name], one’s home, one’s [another hospital name] and one is [another hospital name].

Interviewer: Crikey, so you’re going to get to know all the local hospitals. Have you not been to all those appointments yet, you’ve not had to do that yet?

Parent6 We’re waiting for those ones, they’re the next lot. When she was born, because we were in hospital so long, we’ve missed a lot of the bulk because they did them when she was an inpatient.

Interviewer: You stayed in hospital after she was born when she was little.

Parent6 We were in for a week because she was in special care. If not, we’d have to go to [another hospital name], we’d have had to go two other appointments and one of them is [another hospital name]. Our cardiology is just the [another hospital name].

Interviewer: What sort of problems does that present? Are there additional problems of multiple…?

Parent6 The [another hospital name]is a three-zone ticket, so it’s about £9 for your bus and sometimes more for the third bus.

Interviewer: You can’t use your pass for that.

Parent6 It depends. In [town name] you can only use your pass between certain times of the day.

Interviewer: You might not be able to use it at the times of your appointment.

Parent6 Yes, you can only use it in off peak times. You can only use it between 10:00 until 2:00 in town and then 4:00 until 6:00.

Interviewer: It’s when they’re not busy with other people with work traffic, rush hour. I think we touched a little bit on the food. Have you had experience of having to buy food either while you were in hospital when [child name] was born?

Parent6 When we were an inpatient, they didn’t feed the second person staying with you, someone had to bring it in or you had to do a Pot Noodle, but I can’t see it being nutritionally balanced.

Interviewer: It’s not great. Is that the only thing you could do, a Pot Noodle with a kettle?

Parent6 No, they had to fill it up and you could only have in an hour’s timeslot, a two-hour timeslot a day.

Interviewer: They wouldn’t feed you even though you had to stay.

Parent6 They fed me, but my mum was staying with us.

Interviewer: I see what you mean, somebody else.

Parent6 As my mum said, if it was means tested and ones who could pay paid £5 a day or something like that and they got the same meals as the patient or had a choice. That would be beneficial.

Interviewer: Better than a Pot Noodle.

Parent6 If not, it was ordering off Just Eat and you know how expensive that is.

Interviewer: That’s something else that’s come up if you’re in the hospital setting what’s available to you is not necessarily affordable or what you would be spending to eat at home, is it?

Parent6 I’ve got quite a set balance at home. I’ve got my spreadsheet balanced to August.

Interviewer: You sound very organised. Are you getting a bit restless [child name]? I’m keeping your mum too long.

Parent6 The food in the hospital, it’s not conducive to low cost.

Interviewer: I work at the university, but we’re based in the hospital or near the hospital. If you ever pop into the Costa or somewhere to buy a snack you don’t go back really, do you? It’s very expensive.

Parent6 When we go through, I try and pack snacks for both of us.

Interviewer: I was going to ask you about that. If you can it’s better, isn’t it, if you can take your own. If you’re in for a long period of time or an overnight stay you can’t really do that, can you?

Parent6 Even if I was in with [child name] overnight, they don’t feed the parents.

Interviewer: That’s tricky, isn’t it?

Parent6 I think it’s diabolical when they’re this age.

Interviewer: You can’t leave them, can you, and you wouldn’t want to.

Parent6 With COVID you’re only allowed five minutes. In all fairness, the cafes haven’t been open to the public in the [NHS Trust name]. There has been nowhere to get food.

Interviewer: Was that just during the COVID period?

Parent6 I don’t know if it’s open now or not because luckily enough we’ve avoided the place.

Interviewer: It’s good you haven’t needed to go.

Parent6 Even if they could say, “There’s a voucher. You have to go down to the café and get it, but there’s a ticket.” Something like that.

Interviewer: That would make sense, wouldn’t it? It would be a big help. Were there other things you needed when you were in? Toiletries and that type of thing, were they provided?

Parent6 No.

Interviewer: Nothing like that, so you had to do all that yourself.

Parent6 I know the Mothers’ Union do a very small amount of emergency toilet bags because my mum is one of the dummies who does them. She’s a written dummy who does them, we really do them.

Interviewer: I’m getting nice smiles now, hello.

Parent6 There are only 10 of them a month per ward.

Interviewer: Ten bags of toiletries you mean.

Parent6 Yes.

Interviewer: A month, it’s not very many.

Parent6 The Mothers’ Union can’t afford to do anymore. Even if there was a toilet bag or essentials.

Interviewer: Just take the pressure off, wouldn’t it? What about the way you are spoken to and given information about [child name] or your own healthcare, how has that been?

Parent6 They don’t do it in English jargon, they do it in consultant jargon.

Interviewer: They don’t do the plain English.

Parent6 They do it in mumble tones I call it.

Interviewer: Not speaking clearly you mean.

Parent6 It’s like, “It could be this, it could be this, but we could try this.” Thinking in your head and thinking out loud at the same time.

Interviewer: Not very definite you mean.

Parent6 I’ve got autism as well and I said, “I want an A, B, C, D, E clear plan of what medication she has to take and when.” A lot of them aren’t happy to do that.

Interviewer: Do you feel like you could benefit from having clearer information from them?

Parent6 Even if they said, “We think it’s this or this. This is how you could treat it and this is how we are going to treat it.” We don’t need to know about the different parts of the body and how they work.

Interviewer: If you don’t need or don’t want that knowledge, you don’t want to be told all that, you just want to know what to take when, sort of thing.

Parent6 They would go on about this linked to the colon and this linked to this. I said, “[ \_\_\_0:24:31] link between the colon and the stomach or the liver.” That would be enough for plain English. Then you could ask if you wanted more.

Interviewer: You don’t need the real technical medical terminology. You will at least or you have been a bit already, involved with lots of different specialties, like the speech and language therapy and different specialities. Do you have any experience of whether they communicate with each other?

Parent6 No, they don’t very easily. They only do in my case because we’ve got social services involvement and we’ve got someone physically monitoring that.

Interviewer: Do you think that would be the more…?

Parent6 It doesn’t work. I’ve got experience from my friends that it doesn’t work.

Interviewer: They have to keep repeating the same information over and over.

Parent6 What I do, I take the hospital letters with us when I go.

Interviewer: [child name], are we getting near the end? I think she’s had enough, hasn’t she?

Parent6 She likes sitting like a dog.

Interviewer: I’ll let you go in a minute Resp. Is there anything else that you wanted to say or things you think could help people on a low income to engage more with services?

Parent6 Not to have to wait three months to get their money back.

Interviewer: What do you mean by that?

Parent6 If you do it through the benefits you have to wait up to three months to get your bus fare back.

Interviewer: To claim for it.

Parent6 Yes.

Interviewer: I think it’s probably time to call it a day, isn’t it? I think [child name] has had enough. If there’s anything else you think of that…

Parent6 I’ll email it through to you.

Interviewer: That would be brilliant. I really, really appreciate your time. I hope it all goes well. She’s absolutely gorgeous, she’s got the best smile. It was very nice to meet you both.

Parent6 Thank you very much.

Interviewer: Thanks again Parent6.

Parent6 If you want some more information, I can give you the name of a group and they’ve all got children with disabilities and special needs. You can maybe have a word with the group leader and potentially come out and speak to them and you’d get a wealth of information.

Interviewer: That’s really helpful, thank you. Do you want to email that through or text it through?

Parent6 I’ll email that through for you.

Interviewer: That would be lovely. Thanks very much, I appreciate that.

Parent6 I can send you a link to their Facebook page if you can access that as well.

Interviewer: Okay. That would be super, thanks very much. I appreciate it, that would be really good.

Parent6 They’re always having problems with different services and communication.

Interviewer: They’ll have a lot of experience, won’t they?

Parent6 I’ll do that for you now.

Interviewer: Brilliant. Thank you so much, I really appreciate it. Enjoy the rest of your day. Bye for now.

Parent6 Bye.

END AUDIO