

## **Supplemental Material S2.** Additional quotes for each theme and subtheme.

### **Parents**

#### Theme 1: Appearance of the Device

##### Bullying, teasing and staring

*He didn't like people staring at him because he had the band which was visible.*

*We started out with like a girl's head band. It was kind of old-fashioned . . . and actually he started to complain because he looked like a girl.*

*At first it was definitely "I don't want to wear this, I'm not a girl."*

*I couldn't bear the thought of him going to secondary school with microtia because that's bully-fodder.*

##### Nonuse of the device

*He was just at the wrong age. He was like "That's for little kids." And it makes you look different. You know, as you get older you don't want to look different.*

*It is tiny, it's a fantastic thing, but when it's attached to you, it's a part of you, it's not as discreet as I think she wanted it to be.*

*He does wear it at home but I struggled to get him to wear it at school and it's because of the appearance.*

*One day I get a phone call from the school saying he's thrown it over the fence. I don't know if he was getting the mickey taken out of him . . . because it's on a hair band.*

#### Theme 2: Parental Roles and Responsibilities

##### Decision to have an implanted device; Use it

*I think that at the age of 10, although I totally agree they should have that choice, they're still very young to have an understanding of what that choice is. Because you know, it shouldn't be the parent's choice, it's up to them if they want to have the hearing.*

*I think we were told that the BAHA may be a possibility, and we just felt that given that she might choose to have the jaw operation and all the other poking and prodding she's had throughout her life, it kind of felt like, what, something else? So we felt it was another massive operation to go through, incredibly invasive and we didn't know what the outcome would be, if it would make that much more difference or the quality would be that much better than the one she can just wear.*

*She was all for the hearing aid, she was really excited about it, it was her choice to have the hearing aid, the magnet put in.*

*I tried blackmail, absolutely everything [to get the child to wear the device].*

*I think he has come to the certain age, he can decide for himself, so I respect what he really wants to do.*

*We wanted to see what the options were for him, and you know, he's old enough and he can decide for himself. And he has just had enough.*

*[Make the same decision again?] No, because I actually think that she would be alright in life with just one side of hearing, because she compensates. . . . But it's a difficult question, because I don't know whether or not her change in her academics*

*is because she has matured, and because she's quite studious, and she teaches herself and she's quite committed in that area, or whether that's down to the hearing aid. . . . I don't think it was really necessary to do it when we did it.*

*[Regarding decision not to have BAHA] Partly because, we also knew that we were going to see the maxillofacial people as well . . . talking about potentially lengthening the jaw. So I guess we've been focusing more on the aesthetics.*

#### Information-seeking and getting support

*I think there were gaps [in information], but I'm also not sure if it was so much information at first that I didn't take it in.*

*We have support from the TOD pretty much because I jumped up and down saying "Is anyone going to help?" We had to fight to get that written into her plan.*

*I feel like I had to search. I had to do a lot of research myself. All of it.*

*We've had all kinds of information and I think that's the benefit of being here [specialist hospital].*

*No, I wasn't told anything in all honesty. There was a focus on the [name of syndrome] but there wasn't really a focus on how that [the hearing] would impact on her ability to play or hear what was going on at home, never mind nursery or anything else. I was quite shocked really. We certainly weren't linked in with audiology much until the last few years. So for me, I had no understanding at all except for the research I was trying to do.*

*There wasn't any information for me. The hospital hadn't seen a case like this before, so until 3 months old we didn't know if she could hear or not.*

*When [child's name] was born I was told "Your baby's fully deaf." Then they just left him. Left him until he was 8. They said "No, he doesn't need anything." And it was just left until I contacted [local hospital] and he was referred to [specialist hospital].*

*I did actually make a very big complaint because we weren't told she had the loss of the hearing at the [local hospital].*

*I want to know because I want to know that I've covered all the options. So I do feel a bit sometimes that I have to push to know more.*

*Sometimes you just get overwhelmed when they are little, with so much stuff. (GP6)*

*It's just a constant battle . . . now in secondary school they have a learning support unit, that is why we chose that school.*

*When he [Consultant ENT surgeon] retired, then she got discharged, and so I sort of jumped up and down a bit and said "I think she still needs a little bit of help!"*

*I always have to make sure he's sitting at the front, better ear. And I always say to him "Where did you sit today? Make sure you're always at the front." Just constant, and some teachers can't always remember.*

#### Timing of interventions

*That young period, it's quite critical in terms of learning and talking.*

*I would like it done at a younger age so that it becomes normal sound for them, and they're growing up with it rather than throwing it at them when most of them are 7 or 8 at that time. They are so used to that one side, so it's got to be when they're younger.*

*He could have done with it sooner because he couldn't hear the start and end sounds, so he'd already got the habit of saying his words without the start and the end.*

*I would have liked it a lot sooner.*

*So I think early intervention and adaptation did really help my son wear the hearing aid more often, so now he accepts it.*

*The hearing didn't really come into it until she was in the middle of primary school, so I think Year 4 or 5 was when things were being addressed about it. Actually from birth to Year 4 at primary school nothing was done about it. So actually, on reflection that's quite bad isn't it?*

*I think babies should be offered them. I do not think there should be any wait . . . so they can hear all those sounds.*

*We had a hearing test at 6 days old . . . then we were connected to the hearing support services who came to visit us at home, but there was never any real check-ups with audiology until he got a bit older. Then they put a BAHA on [age 3 years], and I realised there's sounds he's never heard before, then I realised actually his hearing is really quite low, and perhaps they should be doing more.*

### Theme 3: Being different; Achieving normality

#### Bilateral hearing

*I think on a learning impact, I know for sure that it will have a massive impact on his learning, even if he has one good ear, but if it is two, then it can normalise everything.*

*So I am wondering whether one ear can really adapt if you are just having a conversation normally, but in the class? That's my dilemma.*

*What schools don't understand is you have two ears for a reason. So they think because they're communicating with the kid and the kid is answering back, they think he's hearing, but when you put the kid in the background noise situation, . . . the kid will struggle.*

#### Pretending to hear

*He keeps claiming "I hear everything." But I think he is still missing because I see reports saying he's not paying attention half the time.*

*Previously when she didn't have the hearing aid, she couldn't always hear, and she wouldn't always put her hand up to ask any questions because she didn't hear it or didn't understand it.*

*They always claim they can hear.*

*I think sometimes he's a bit in denial as well. He says he thinks he hears.*

#### Feeling different

*He tried it [Sound Arc] and he didn't feel the benefit he was getting was any different than what he was doing with one ear. And it was, again, he was feeling different, and he didn't want to be different.*

*And it makes you look different. You know, as you get older you don't want to look different.*

### Theme 4: Impacts and implications of hearing loss

#### Speech

*He was behind [at school] and the speech did have an impact on that. People not understanding him because of how he spoke.*

*It affected his speech as he was growing up, because can't hear —can't speak.*

*I realised [there are] things he can't hear, a lot of stuff, and other people understanding him. But you tune in to your own child's way of speaking. . . . Other parents not being able to understand what he's saying even though I could.*

*I think the main thing that's affected him, development-wise, . . . when he was younger he had a SLT, they told me he was behind.*

*I think because of not being able to hear and because of the constant glue ear, then the speech problems, and she's got a learning difficulty as well, so not only can't she hear, even when she does she probably doesn't quite understand all of what is said.*

#### Psychosocial/independence

*He is social [but] the way he attacks social situations, it's definitely different. It's interesting because I have a daughter who is normal, and she isn't as good at school, but she is much better socially.*

*That [the hearing loss] has massively held her back . . . the opportunity to have a hearing aid has been brilliant and that has really helped her confidence . . . so now she feels she's part of what's going on to a much greater degree.*

*And I think I probably kind of just changed, because I was always so paranoid because everyone used to say you always baby him, he will never learn how to grow up, or learn to stand up for himself. I think he is quite mature for his age now, he's only just 13.*

*I think it is potentially going to start having an impact on him socially, because you know, if some of his friends might want to go to those places and he is choosing, I don't want to be in these places because I don't like the noise around me. Like going to restaurants, he just sits there and is like "Can we leave now?," cos there is a hubbub of noise. He'll probably not be one of those teenagers wanting to go to the pub because it's not a good environment for him.*

*I think not being able to locate sounds has delayed her independence. I've struggled a bit, her dad I suppose more. Where everyone else walks to the bus stop at secondary school. She's got to cross two major roads which her dad used to just sit and watch her cross. But you've got to let them go at some point. And I'm like "Don't put your hood up when it's raining, use an umbrella." So I drive her. It takes just one person not to see her or she can't hear the car.*

*Everyone around him, except me, was like "He's normal, there is nothing wrong with him." And I'm like "He is not, look at him." He's kinda got that attitude now actually, which is not a bad thing because now he's got confidence.*

*(As if talking to child): "You are going to have to support a family one day, or at least yourself. I am not going to be able to bail you out forever."*

*She is confident as a person and what I try and teach her is don't compare yourself to anybody else.*

*I think [child's name] had become very reliant on that TA, and so now he's having to learn a bit more independence and having to listen to what the teacher is saying, rather than just drift off.*

#### Cognitive/learning

*When we're outside she often won't wear her hearing aid. I think that's sensory overload, she gets tired. She goes to her bedroom, shuts the curtains, and it's like, "I can't deal with any more today, I'm absolutely wacked." She is very tired, I think from a mental point of view, fatigue, throughout her whole life really, it's a massive thing for her. That extra effort of having to try and hear what is going on around her, which I forget.*

*I mean, he's very, very bright, but he suffers academically.*

*I do worry when he moves to senior school next year, that things will get louder, more kids, more difficult, and I'll just watch his grades because at the moment, I can't complain, he's very clever.*

*I actually believe that at the time that he did have the BAHA . . . when his development was critical . . . that's obviously why he did so well at school at that point. And that's when he really made that progress.*

*I think now it's not as bad as what it was when she was younger. . . . when she was at primary school, I think it affected her learning needs. She was below her academic year throughout the whole of primary school.*

*We wanted to try it [the BCHD] because learning, the school aspect, that was a massive thing. . . . And she loved it when she could hear something.*

*I get that in [child's name]'s report, he's easily distracted.*

*She was very exhausted for a long while, really exhausted by suddenly hearing everything.*

#### Accommodations

*It's just a constant battle. . . . That is when I moved schools. . . . now in secondary school they have a learning support unit, that is why we chose that school.*

*In most cases he'll sit at the front. He'd rather not have to position himself in the classroom.*

*He knows where to position himself if he can't hear. He found classroom discussion quite hard because he can't tune in. Especially teenage years, they don't listen to anybody and he can't pick out a particular voice, so it's just a noise to him. So he doesn't like group work.*

*The setting he was in was perfect for him because he had access to the mainstream, but still for his learning, it was in small groups. And obviously in much quieter environments, so his attention could be got.*

*[Re spelling] and she has support at secondary school as well. And throughout primary school she had the support.*

*That's why I moved schools: he was probably about 2 years behind in school, and it took 6 months to catch up. All the school did was take him out twice a week for half an hour to read.*

*He started at a unit in the mainstream school, a special needs unit, and he had a lot of help and support there. . . . and in those 3 years at infants he went from being a very poor kind of special needs student to the low end of the mainstream.*

*She sits at the front of the class, so that she can hear better . . . And making sure all the teachers are aware.*

*He is trying his best to be in front of the teacher.*

*Like on the tube, if she has her baby ear facing me, she turns around saying she can't hear. I didn't realise all she hears is the tube, all the noise going on, and she would blank me.*

## Children

### Theme 1: Psychosocial Issues

#### Feeling Different

*Even some teachers ask me and most of them say it's actually really good to talk about it so other kids can look at it and be fascinated or have their own opinions.*

*(Re being asked questions) I know that I wasn't born what I'm supposed to be, and I was born different from a lot of people. So I just give them the answer and they just shrug it off and say, okay. It doesn't really bother me.*

*For me at school I haven't been treated differently because I can't hear well. Everyone sort of treats me the same.*

*It makes a lot of noise and everyone looks and stuff.*

*I don't mind people asking questions. If they don't know they don't know how to react.*

*(Re decision not to have implanted BCHD) I don't think so. Because now there are people who judge you based on the way you look, so I will get a bit more picked on, and likely will talk behind my back if I wore one. Not my friends, but people that didn't know me, and I will be looked at a lot and sometimes it gets a bit annoying.*

*I get judged differently at school as well. My teachers have to ask me "Are you sure you heard everything?" And my friends.*

*[Re being asked questions] I really do not mind. I try to be polite and tell them what they want to know. I find it okay, I don't see anything wrong.*

*It's just the operations. Loads and loads of operations. I just really wanted to be normal really. Um, I really didn't want to stand out from everyone else.*

#### Emotional

*[Re having magnet] 'Cos I hated having the band around my head constantly,' cos then you couldn't do much things with your hair, and it just annoyed me a lot.*

*I can hear my chewing weirdly, that like annoys me because then I cannot hear as clearly.*

*So it's hard, say, if you put your earphones in you can only use it in one ear. So it's quite annoying 'cos people will ask me why can't you put them in both ears and I have to tell them the whole story.*

*Well, with the [soft] band it annoyed me, 'cos it is always there, and it was quite visible, and this one [magnet] you can't see so it doesn't bother me.*

*I think it wasn't really the BAHA, it was more the band—it was light blue, I don't know why as I had brown hair and you could see it on the skin really well.*

*It's annoying 'cos you don't know where sounds are coming from.*

#### Bullying

*'Cos it caused a lot of bullying so I didn't really want it any more. So I ended up throwing it away.*

*It [bullying] started in Year 3 . . . then when I was in Year 4 and 5 they never bullied me because I told them what happened. Bullying happens when new people come.*

*So basically they can take the mick out of me and stuff—when the supply teacher comes in some people don't really do their work.*

*When you go to secondary school, you're always worried about bullying and stuff, but because it [the hearing device] wasn't visible, I didn't care, 'cos no one would know.*

*Sometimes you get weird looks when you come to a new school. They mostly ask you what happened and then sometimes you just like want to keep yourself away from other people, you don't want to be embarrassed by other people.*

*I used to [get bullied] at primary school but since I got to secondary school it's not really happening any more.*

*I walked past them and they talk about me. So I said "You talked about me" then they kicked me and said "you look so weird." Something about that.*

## Theme 2: School Issues

### Listening and Learning

*So, my maths teacher gets angry easily and although I sit at the front of the class she thinks I can hear but when I ask her to repeat it she's like "Aren't you listening to me?" and she gets a bit angry. And I just have to remind her that I have got microtia and that I might need it to be explained one more time. If I do get a question wrong, cos I'm in the top set, and I get upset she asks me why I got it wrong and says "Do you need to be in the bottom set?" And I'm "No, I just need you to explain it more." I just can't hear that well.*

*Sometimes it might affect your learning because when you have to wait in the hospital like for a check-up, you miss subjects, especially when you are into GCSEs and you have to learn a lot of things.*

*Sometimes I can't hear some teachers who are males 'cos their voices are really low, so it's harder to hear them, but otherwise it's fine.*

*Sometimes when I'm in maths some of the boys can be noisy and it kind of disrupts when I'm trying to do my work. It really gets on my nerves.*

*I'd always have to turn right around. I can't really hear well in that ear, so, I have to turn right round and they [classmates] have to whisper to me.*

*If a teacher puts me at the back of the classroom sometimes I can't hear them but usually I can 'cos they're pretty loud.*

*'Cos they will tell us how to do something but I might have to hear it twice. Some lessons they have to explain it twice to me, once for everyone and then once just for me. So I can actually learn what they're saying. I'd get most of it with the class but they'd have to clarify for me.*

*School is definitely one of the hardest places to hear in because there's lots of people chatting around and loads of people being loud and obnoxious.*

*Especially when you get older 'cos they try and get in as much learning as they can. Every lesson is different. So if you miss a lesson you miss a topic.*

*The teacher went "Why are you doing that?" I was like, "Wait, what are we doing again?" They said was I like day-dreaming and I said "No, I was trying to focus on what you were saying but I didn't really catch it." It's really annoying cos sometimes when a lesson ends and then the next one, if we have a double lesson we'll go back into the lesson and pick up where we're from and I'm like wait, what, and I'm very confused 'cos I didn't hear the question and I forgot, and I just lost where we are.*

*I've got this one teacher who looks after the medical records people, and if she sees me a bit upset she's, so if my teachers shout at me because I couldn't hear or I didn't do some of the work 'cos I couldn't hear it and I got a detention or whatever, they would speak to my teacher and just remind them that I do have microtia and that I might need it repeating or whatever.*

## Accommodations and support

*There were lots of TAs so they always came along and helped me.*

*The teachers do not know [about the HL] because I feel no need to tell them unless I need to. We have a seating plan but I do not need to say anything because somehow randomly I always sit at the front.*

*For me, I sit at the front of the class. . . . For each lesson, so I can focus more. (?)*

*I sit at the back in some lessons and I think that's no different really, but my mum asked me to sit at the front so I can hear.*

*I do sit at the front of class for most of my lessons.*

## Friends

*My friends do ask me though, if like I can't hear them, they'll speak a bit louder. They consider it, although they don't ask about it every day. But if they were whispering while we're doing an activity they'd write it down for me as well.*

*Some of my friends talk really quiet, 'cos they want to tell me something, I can't really hear them.*

*When all my friends try to speak to me at once I have to say I can only speak to you one at a time.*

*So I played on my iPad, not with my friends, 'cos I can't hear what they're saying.*

*I would say, if someone would judge you differently just how you look, or something you do, that's not a real friend. A real friend is accepting you as a person.*

## Theme 3: Decision-making and Device Use

### To have a BCHD

*No-one has told me what it would feel like. Yeah, but it was not as clear as I would like it to be. I did not really understand it to the point where I know what he is talking about 100%.*

*He used a few pictures but they were not really very informative.*

*They asked me if I wanted to have the one on the side of my head once. I said no.*

*I thought it would be fine to try 'cos if you don't try you won't know if it will be good or not. I think they put it on a soft band 'cos if you don't want it you can get rid of it easily.*

*Yeah, they talked to me as well. So, obviously, they explained the medical stuff to my mum, and like the operations and stuff, and then they actually explained what it was and what it would do for me, to me.*

*There wasn't really enough understanding of it [hearing options].*

*I found it complicated because I didn't know, 'cos I was like in Year 4 and there was words I didn't understand.*

*The doctor said if I did like the hearing aid, I had the option to have the surgery but I didn't really like it. I was in the room when my Mum was talking about the BAHAs and hearing aids. I didn't feel comfortable having one. I didn't like how it [the softband BCHD] gave me the sound. 'Cos it was quite muffled whenever I used it.*

*They discussed what it would be, what it would feel like, and it would change my hearing and I would probably pick up lots of sounds and stuff. And I know I remember my mum talking to me and asking if I was happy doing it, and I think I just wanted to hear more things so I was.*



*One of them I refused one time 'cos I was scared and didn't have, like, a lot of knowledge of what it is and how it works. But the other two, the abutment and the soft band, I just agreed because basically my mum was encouraging me to use it.*

*[Regarding discussions] I didn't really get involved in it but I remember when my mum and a doctor. . . . I listened but I didn't really talk.*

*I was given a lot of information. When I was younger they usually focussed on telling my mum 'cos I wouldn't listen. And then afterwards, when we were in the car she would tell me. She would repeat it and I would understand it. Now I've definitely been in the conversations way more than I used to be, because I am a bit older.*

*I think if people knew from our side what it felt like a bit more to be making the choices and then if we were given diagrams of what it would be, and the end result and the middle result and before, then we would probably be able to be more open because right now the BAHA, it is kind of a one way thing, because if I get it then I might regret it and hear the buzzing noises again.*

*Yeah, I think it's at the exact right level for me. 'Cos it's at that level that it's not really easy to understand, but it's not really hard to understand. It's like middle, which I am at the moment.*

*I think to me, my hearing's alright and I don't really want to go through that just so I can hear a little bit better.*

*For me, I've always said no to it 'cos I don't want to have another operation.*

*They gave me a choice about it. But my mum gives me the option too. . . . But she'll let me do the final decision. She won't think it's right that she chooses for me.*

*When they talked about it it was more about technical [things]. How they make different sounds. But they didn't really tell me anything about it, and I didn't really like it in the end anyway. So I got rid of it.*

*I didn't really like it [soft band] so I didn't go any further with it [surgical options]. I think that was the case that the surgical one might have been better as you don't see it so much.*

#### Using a BCHD: Benefits and problems

*It was uncomfortable. I think it made it (hearing) worse because it was too irritating. I couldn't focus in and hear.*

*Sometimes when I used to wear it, I got this really loud ringing noise. It was like when it was windy, it didn't sound like the wind, more like whistling. It was really irritating.*

*Well it [the BCHD] did make a slight difference. But I don't think it made a big enough difference to me to wear it all the time.*

*I've learned to cope with just hearing by myself not with the BAHA. So it helps, but not all the time, because when you're wearing it outside and it's windy you can basically just hear the wind.*

*Sometimes, when it's really windy, it's like swishing sounds in my ear.*

*For me, I do not think I really mind the way it looked. It was mainly just the sound.*

*When I took it off it was quite screechy, so it annoyed me a bit.*

*When I was at school with the BAHA, before the BAHA it was normal but when I got it, it was so much louder, and it was really difficult to get used to because it would just give me headaches all the time. 'Cos I think they set it a bit too high, so that it was a bit too loud, especially when you have got everyone talking in the class. Sometimes it gets a bit over the top.*

*It's at my old school. So I took it off the band and threw it over the fence. It might still be there.*

*When I had it I was able to hear more but I'd always have headaches and go home.*

*I prefer this one [magnet] because you can't see it at all.*

*It helps with, like, watching something, like when you're listening to someone and there's some other people talking, you can just hear the other people.*

*[Re: soft band] Sometimes it was uncomfortable, and like when you had to tighten it so it would fit your head, it would just slip off a lot. And the hearing aid would make a racket and everyone would look at you and that kind of thing.*

*When I first got it the magnet was way too strong and it really hurt my head. I had to take it off during school which made me lose it once.*

*I think I've tried all the different types, like the abutment and the band and the magnet. So I think mostly it's easy, but sometimes it's kinda hard, 'cos you have to like adjust to it. To fit it in.*