R: What is Harry’s date of birth?

P: \*\*\*

R: Does your child have an identified special educational need?

P: 2

R: Which are?

P: He has for quite some time had a diagnosis of expressive developmental language disorder which is a communication difficulty and this week we’ve had a confirmed diagnosis of autism.

R: And does your child attend mainstream or special school and what level are they at?

P: He is in mainstream secondary school at the beginning of year \*.

R: Super. Right. So basically, what I want to do is to get your impression of the body mapping task – what you thought of it. What you thought the pros and cons of it are. And be completely honest please.

P: I thought it was absolutely fascinating and I found it really hard to stay quiet because I found so much of the process and what he was saying absolutely fascinating. I felt it was a really clever way to get somebody to talk. He is generally quite self-aware but isn’t always very good at talking about it so in terms of supporting conversation I thought it was incredibly useful. I was fascinated by some of the choices he made and some of the things that have come out of that conversation have led to subsequent conversations since that would be really helpful so perhaps beyond even what you were aiming for it to do it has done so it has been really helpful. The one observation I had was a lot of that came because he was having a conversation with somebody other than me. Um, in that. No, I shouldn’t generalise it. P is a child with communication difficulties and will at times ask or rely on me to understand what he means or fill in the gaps or communicate for him and as a result I think if you are looking to adapt the process for coronavirus I think you would be better to do the online version because although it is not as physical and not so much fun, the underlying bit is the fact it would be the conversation with somebody other than his normal communication support whoever that might be his parent or whoever. I don’t think we would have got as much out of it if he had done the whole thing with me. I think we would have got a lot less so the online version may not be as creative, it may not be as fun, but it still prompts and supports a conversation. Does that answer the question?

R: That absolutely answers the question. That’s fabulous. Were there any negatives? Were there any things that you thought that’s not going to work, he’s not going to like that, or it would be better if it happened in a different way? Anything you can think of?

P: I was worried – given that he’s … one of the things he struggles with is making choices and making decisions and depending on his mood or the time of day or everything else that’s going on in his life at the time that can be as simple as what to eat for breakfast so I was worried that he was going to struggle to make the choices about what to say, what to talk about and what materials to use. My feeling was that well, we are not the most arty or creative family and I thought that might be a barrier for him and I was surprised to find it wasn’t and I was interested in the choices he made because of that so no I didn’t see any massive barriers. The only other thing was I was worried that by being there he was looking to me to influence some of the answers he gave so it took a lot of me being very, very conscious to bite my tongue and not speak for him at times so that would be something that you might need to brief people on. If they need someone there as a support just to brief them on to say please bite your tongue. I know I didn’t do that all of the time so it’s a really careful balance to strike because at other times I could see that he had more to give and to talk about so was trying to ask a sensible question to get him to think about it without giving him the answer so I was trying to be good but you know. It’s really, it’s difficult to know where to strike the balance so maybe some briefing for anybody who was in the room as to how much you are happy for them to intervene and how much they should bite their tongue.

R: Excellent

P: So, no massive drawbacks at all.

(6.46)

R: Anything else that has struck you since the activity.

P: No not really. That’s not really very helpful I know because actually I know when we give feedback to trainees, they don’t like the yeah it was all great feedback.

R: It’s all very helpful. You have said quite a lot and I think I have a lot to go on. I do think it’s interesting that you’ve said it has prompted conversation since. I think that’s definitely valuable to know.

P: It is really, really helpful conversation. The bit that really mattered – you could probably see me doing a little dance around the room. He was talking about meltdowns and he said that I helped him get out of meltdowns and he identified me as part of the solution not part of the problem. An as I said – as I think both of us said – it’s a different person that he fixates on as the problem each time so even though I can be the problem and the cause of the argument or the baddie in the argument he is still there and turning round and saying I’m the solution in the meltdown and I was talking to him about it this morning and asking him if he felt there would be any merit in us either getting somebody to help him, talk to him about the meltdowns and how he could cope with them or maybe us doing it ourselves so that we could have a plan because during his OT assessment he confessed that he can feel it building so I said to him if he can feel it building maybe we can put a plan in place so that he knows that he can take himself out of the situation – sort of stop the world I want to get off, go and calm down, and we can have a pre-agreed list of questions or a problem solving process where we could talk about it and solve the problem before it became a violent meltdown and on the one hand he was saying I’m not sure it would work because when I feel like that I forget about all of those plans and on the other hand he was saying maybe I can see it working because if we’ve got a list of questions then I know what they’re going to be. The real break though is the fact that he’s prepared to acknowledge those meltdowns and say there might be something we can do. It won’t work every time, but it might make the duration of them shorter. A bad one can last half a day so it would be good if we could make it shorter or just him also realising that he needs that space to go and calm down. One of the problems we have is that whoever it is that he is fixating on will need space to calm down and he follows them around. He won’t let it go so all those easy sort of bits of advice they say go and cool down. He won’t let you do that to the point that he can unlock our bathroom doors and I have been known to lock myself in the bathroom and he will follow me in so I really cannot escape to calm down and give him the space to calm down and that makes it really difficult.