**Notes from visit (13th March 2014) for Favourite Thing Interview with Sean (12).**

**Sean’s favourite things:** Four caps (including a Chelsea football team one and a Ferrari one) and a bandana, two silver car toys, an electronic picture frame with various photographs, an iPad with photographs of three new pairs of shoes and a video.

I arrive at the school forty-five minutes before the interviews are due to take place and have a short catch up with Linda, who has been my liaison at the school. We go an empty classroom where the interviews will be held and we have a quick cup of tea whilst I ask her some questions about the boys. I give Linda two envelopes with the consent forms and a voucher each so that she can pass them on to the parents. Various people come and go from the room, with staff taking the opportunity to use the empty classroom’s computers for work. Linda explains that she has spoken to Tim and Sean about the research earlier in the week, talking them through some of the questions I’d sent in advance. She tells me how they’re both very excited and that their parents have also been enthusiastic.

We discuss the seating arrangement and Linda suggests that a circle will provide a more informal feel for them. We also pull over a table to put their two large rucksacks of favourite things on. It’s agreed that the interview will be a joint one, as this will place less pressure on both boys. Linda warns that they’re both in a bit of a ‘CBA’ (can’t be arsed) mood today, so they might seem less engaged than normal. We briefly go to say hello to Sean, who has an oxygen mask over his face but he’s not very responsive. Sean, who is twelve years old, has X-linked Adrenoleukodystrophy and is in a wheel chair with his legs placed at a horizontal angle. He also has epilepsy and needs to be tube fed. He is unable to communicate verbally but generally has a good level of understanding of what others are saying to him. He uses visual communication aids and a communication app on his iPad. However, for our interview he only communicates with a subtle raise of his hands to indicate ‘yes’ when asked questions (no movement means = ‘no’). Linda explains later on that Sean’s condition developed whilst he was in primary school and that he has not always been disabled. Apparently he has chosen a number of objects from his past, which are linked to the time before his condition became more acute. Linda asks that the interview questions not explicitly refer the onset of his disabilities.

Back in the classroom Tim and his carer, Helen, join us. Tim is fourteen and has Downs Syndrome, Asymmetrical Spastic Diplegia and Cerebral Palsy. He is in a wheelchair and is able to navigate himself using a joystick. Tim has some limited verbal communication, but also uses visual communication aids. Linda introduces us and Tim offers me his hand to shake. He’s quite warm when he comes into the room and Linda helps him to take his jumper off. We talk for a little while about his day and whether he has been looking forward to talking about his favourite things. Tim mostly provides single word responses (often just yes or no) and occasionally signs or makes noises to add further clarification or expression. After a while he loses interest in our conversation and asks for one of the classroom iPads. At first he’s unable to switch it on, and Tim presses the home screen button to try to get it to work. Linda struggles to find the on switch and I point out that the plastic case looks like it’s on upside down and is blocking the on switch. Even with the iPad the right way up, it won’t switch on so Linda finds a lead to charge it up. Once they manage to switch it on, Tim begins flicking through the apps until he gets to the camera app. At first he looks at his own reflected image from the front facing camera, and he plays around with a variety of distorted mirror effects. Tim then goes to the iPads camera album and browses through portrait pictures of an older girl with a nasal tube. He points at the screen and asks ‘me?’, and Linda say that it isn’t him. She tries to work out who it is and then realises it is a girl from the school who has recently died. Tim browses through more pictures of the girl, swiping back and fourth. Linda asks Helen if Tim knew her and she says it’s unlikely as they were in different wings. Tim gets a bit frustrated with the camera app and appears to be trying to get back to the camera screen. Linda tries exiting the app for him to get it back to the camera and Helen turns the iPad around so that he can see his own reflected image again. Tim beckons Helen to pose in a photograph with him, whilst Linda holds up the iPad and presses the button to take the picture. At this point we only have an hour left until the boys need to get ready to go home, but Sean is still in the bathroom. It’s decided that we’ll start the interview with Tim and then bring Sean in once he’s ready.

I ask Tim if he knows what the sound recorder is. He doesn’t give a response so I go on tell him that it will record our voices so I can listen to the conversation again later. He takes the recorder and then mimes speaking into its microphone – I take this to mean that he understands what it is for. I also show him the iPod touch and ask if it will be okay to take photographs of his favourite things. The interview ends up being a fairly free-flowing discussion and it quickly becomes apparent that many of the prepared questions would be difficult for them to directly answer. I decide instead to focus my attention more on their body language, facial expressions and hand gestures as a way of learning how they feel about the objects. Toby is very excited to go through his objects and Helen takes them out of the bag one at a time. Helen provides some context about the objects, with notes written on the backs of the photographs from Tim’s parents. We look at the photographs of some of Tim’s dogs, past and present, and Tim kisses the photographs, rubbing them against his face in an affectionate way. Apparently he only has one dog at the moment, but there is a regular cycle of working dogs coming through his house, as both of his parents are police officers. Dogs are one of the few animals that Tim isn’t scared of and he smiles a lot whilst looking at the photographs. We also look at his Star Wars lightsabre but he isn’t able to get the green blade to come out at first. Linda presses a few buttons and the blade eventually comes out. Tim then waves it around and makes ‘vrrrrm’ noises to imitate its sound. We go through a number of his favourite picture books, which include Ben Ten, Star Wars, Spiderman and a Take That annual. Apparently Tim is a big fan of Take That and he kisses the images of several of the band members inside the annual. Linda explains that he doesn’t like having his haircut, but recently this has changed as his hairdresser has begun to give him a ‘Robin Williams’ cut. Tim doesn’t pay a lot of attention to the Star Wars book, and briefly flicks through the Ben 10 book. He stops to look through some of the pictures from the Spiderman book, pointing and smiling at pictures of Spiderman. We look at one photograph of him swimming in a pool on his last family holiday. Tim points to a woman in the pool with him and says ‘mum’. Tim also has a DVD of the Incredible Hulk, which he waves around. I ask if he watches a lot of films at home, and he makes the motion of a steering wheel. Apparently the school bus has recently had DVD players and screens installed so he is able to watch films to and from school.

Whilst Tim has been showing me his last objects, Sean has arrived in the room with his carer, Karen. We continue to look at Tim’s objects, as Sean is having his shoes changed and his legs placed into a more comfortable position by Karen. Sean communicates using just a few subtle body gestures during the interview, but smiles a few times when Linda or Karen tell him jokes. One of the first objects that Linda produces from Sean’s bag are four baseball caps. Apparently Sean has a large collection of baseball caps, and often wears matching caps and scarfs. Today he is wearing a bright cheque cap with a matching scarf. Two caps in particular appear to have significance for Sean, a blue Chelsea cap and a red Ferrari one. In the photographs on his digital picture frame we see him sat on the sidelines of a football match, wearing his Chelsea cap and scarf. There are also photographs of Sean in various ‘flashy’ cars, including a Ferrari. Whilst Karen is holding up the digital picture frame for us to see the photographs, she asks Sean if he wants us to continue looking at them or to move onto another objects. He indicates with his hands that he’d like to continue looking at them. I ask if he has the digital picture frame on in his room and he indicates yes. We look at two small silver toy cars from when he was younger, and he gives a big smile as Karen drives them over his stomach and chest. We look at his iPad from home, which has a video of a care worker who has left the school to go travelling for a year. The video shows her on her last day receiving gifts from the staff and students. Sean filmed the video on his iPad by himself. Apparently he keeps in touch with the care worker whilst she is travelling by Skyping her on weekends using his iPad. According to Linda and Karen he keeps photographs and videos on his iPad to remind him of people and events. Whilst we go through Sean’s objects, Tim begins to get bored and starts to yawn and look around the room. I keep asking him questions occasionally in an attempt to help him feel included and interested. Towards the end of the discussion, Tim begins to ‘cramp’ and Karen and Linda have to move him into a more comfortable position in his chair. His breathing is a little erratic and so Karen gently massages his legs whilst Linda tells jokes that help to relax him. At the end of the discussion Karen uses the iPad to take a photograph of Linda, Sean and I to help remind him of the interview.

Once the interview has finished I ask them how they feel about having me spend a day at school with them, taking pictures and recording sounds. Tim seems particularly excited at this prospect. Before they go I take pictures of their favourite things. The carers suggest taking pictures of them posing with their things, and Tim enjoys waving his lightsabre as I take a picture of him.

It’s hard to judge how this interview went. For my part, it was extremely enjoyable to take part in, and I felt that the more informal atmosphere meant that both boys were able to share their objects without the pressure of having to try and communicate explicitly why they had chosen them. Tim’s pleasure of his objects, particularly the photographs of his dogs and his Take That annual, was evinced through his affectionate body language. Sean was less communicative and so it’s harder to judge how he found the experience and whether he enjoyed it. Although less explicit than Tim, Sean still subtly indicated the significance of his objects, particularly in asking the photographs to keep playing on the digital picture frame. Having to rely much more on other adults to mediate the discussion had a significant impact on the dynamics of the interview. They contributed by not only sharing further information about the significance of the objects, but also by helping to engage responses from the young people.