**Notes from final interview and family interview (18th August 2014) with Sean (13).**

Sean’s final interview took place at his family home, located on a quiet road in a large country village. The interview date was arranged in advance with his mother, Valerie, who I hadn’t met in-person up until this point. Both Sean’s dad and brother were out of the house, and so the interviews involved just Sean and Valerie. Apparently Sean had been having a short nap until the point where I arrived and so he looked a bit bleary eyed for the first part of the visit. One of the first things I noticed going into Sean’s house were the sheer number of photographs lining the walls, with various family members. There also appear to be quite a few of Sean and his brother growing up.

Leading up to the interview I had been quite nervous about showing Valerie and Sean the day in a life fieldnotes and the multimedia document. As Sean’s day had been with constantly interrupted by discomfort and pain, I felt apprehensive as to how the family would feel seeing his distress overtly depicted in the research. My worries had, however, been unfounded and Valerie said that she and Sean were both really pleased with the fieldnotes and the multimedia document. Valerie explained that at that time Sean had been progressively experiencing higher levels of discomfort that had eventually resulted in him being admitted to hospital for two weeks during the beginning of the summer holidays. This has led to a change in medicine regime (his stomach now only accepts the smallest amount of fluids) and also some shifts in his daily routine (more frequent doses of painkillers and his other medicines and a slightly earlier bedtime.)

In advance of the interview, Valerie described how she and Sean had sat down to read through the fieldnotes and the Prezi together. Apparently there was some amusement at referring to him by the pseudonym ‘Sean’ and at one point his older brother came into the room to ask who this story about ‘Sean’ was. Valerie also described it later on as ‘like reading a story’.

As with the favourite thing interview, Sean’s inability to verbally communicate meant that the interviews were more reliant on his mother acting a mediator. This isn’t to say that Sean was ‘passive’ in the interview – and in fact Valerie would regularly encourage Sean to respond to my questions with ‘yes’ or ‘no’ responses. He would also frequently smile and laugh at some of the stories that Valerie would tell, and I got the sense that they had a close ‘conspiratorial’ relationship – with lots of in jokes shared between them. The interview was also tinged with sadness at some points, particularly when Valerie would describe aspects of Sean’s condition. In particular, she lamented how Sean had been a ‘chatterbox’ as a child, and that she now missed his constant stream of talk. Nonetheless, Valerie and Sean seemed to have developed some new ways of communicating with one another, such as by Valerie joking with Sean that he has called her a ‘rude word’ when he’s acting frustrated, and in so doing dissolving his tension through laughter.

In contrast with past research visits with Sean, I felt that this was a much more intimate experience. It had been quite hard in previous visits to feel a sense of close proximity to Sean in the presence of his school carers. To begin with I got the sense that Sean felt quite shy in my presence, avoiding eye contact with me initially. Over the course of the next hour however he seemed to relax a bit more, sometimes looking over at me, and also laughing and smiling much more. Throughout the interview I attempted to direct the questions to both Sean and Valerie in order that it didn’t become a discussion ‘about’ Sean, rather than ‘with Sean. Nonetheless, this was still quite difficult to achieve, as the interview was heavily reliant on Valerie as the principal verbal communicator. For the most part I found myself diverging from the prepared questions, and instead tried to keep it a more ‘informal’ discussion about how they both felt about the materials and the ways in which they will be made publically available. In the multimedia Prezi document there were a few photographs that capture Sean’s face and both Valerie and Sean were happy to keep these in. Whilst going through the Prezi, I held up an iPad in front of Sean’s chair for them both to see. This was perhaps one of the most interesting parts of the interview in terms of observing Sean’s body language responses. For the most part he didn’t seem to be ‘visually engaged’ with the Prezi – often not looking directly at it. Instead he seemed to focus much more on the sounds playing and appeared to smile with recognition at different people’s voices, particularly those of his teacher and one of the girls from his class. When asking Sean how he felt about the multimedia document being published online, Valerie directly asked Sean for a response to indicate if he was happy or not. As on previous occasions, his assent was conveyed by lifting his hands up.

Sean also experienced some discomfort during the interview, and Valerie had to readjust his leg, neck brace and sitting position in order to make him more comfortable. There was a strong sense throughout the interview of Valerie’s role as an almost full time carer to Sean at home. Although they heavily rely on a large support network of school staff, extended family, carers and charities, I also got the sense that Valerie maintains and extremely close bond with Sean. In this respect the interview was also tinged with a sense of Valerie’s exhaustion, (particularly following on from Sean’s recent hospital stay), and how much she was looking forward to a family trip to a holiday park that specifically caters for young people with a range of conditions.

We also briefly discussed the possibility of Sean’s engagement with future research, which both Sean and Valerie seemed happy about. Whilst I was preparing to leave, Valerie said that one of the things she was most pleased about in this study had been that it wasn’t a study about ‘children with disabilities’, but rather ‘everyday childhoods’. She also said that she hoped other young people might see the Prezi and get a better sense of how different and similar Sean’s life is to their own.