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**Students' and their parents' experiences of inclusion in mainstream
schools**

**What does inclusion mean for parents with children that have special
educational needs and what does it mean for the children themselves in
today's mainstream schooling system?**

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In loving memory of my father, who sadly passed away during this process.

Abstract

This thesis examines experiences and critical incidents that parents and their children with special educational needs encountered in mainstream school settings.

Research was carried out within the methodological framework of autoethnography, reflecting the author's desire to make sense of her own experiences of inclusion in mainstream schools, both as a professional 'insider' and parent of a child with special educational needs. A purist approach to autoethnography was used, where stories were seen as stand alone pieces of gold: individual, unique case studies giving rise to questions and emotions in their own right, (Ellis & Bochner, 2006, Vickers, 2010), combined with the rigour of an analytical approach to make sense of what unfolded (Andersons, 2006).

Differing meanings, values and interpretations surrounding inclusion have shaped the current inclusion discourse and understandings of 'need' and 'disability', giving rise to significant impacts on the disabled person and the symbolic value of the disabled body. The work of Bourdieu and Foucault was used to better understand concepts of capital, power and agency and the impact these have on the disabled entrepreneur.

Research findings indicate that positive experiences of parents and children with SEN in mainstream schools were rare and sporadic. However, success is possible if we redefine the language surrounding SEN, taking a more detailed and sensitive approach that recognises the power of words in shaping values, attitudes, feelings and practices. A more equal distribution of power is required to stabilise the SEN system, listening more to parents and children and empowering them as agents of their own lives. Standing in people's shoes, seeing them as valued, unique and capable, as wanting to find their true abilities and to realise their hopes, their dreams and their full potential will lead to the term SEN no longer being necessary.

Index

Introduction (page 5)

Chapter 1 My Story (page 6-16)

Chapter 2 An Autoethnographical Approach (page 17-52)

Chapter 3 Contextualising Special Education Needs and Inclusion (page 53-105)

Chapter 4 Stories Told (page 106-136)

Chapter 5 Unearthing: Finding the Issues (page 137-173)

Chapter 6 A Long Road to Discovery (page 174-189)

Appendices (page 190-210)

Bibliography (page 211-239)

Introduction

What is it about?

My thesis investigated what experiences of inclusion did a parent of a child with Special Educational Needs (SEN) have when their child attended a mainstream school and what did the child experience.

I have examined the journey a parent embarked on when they had a child with SEN attending school in the mainstream system. I have examined the critical incidents, which have occurred and are still occurring. I have then asked each parent's child about the same journey. I have examined positive incidents and negative incidents and have identified themed commonalities or exceptional experiences across the stories told. This information has then been used to help shape my developing perceptions and findings on inclusion and provision for the child with SEN in a mainstream environment.

To help you, the reader, better understand why I chose this research question I have written my story entwined with my son's, Nick, story, which serves two purposes: 1) to set the scene and to give you a greater insight into why this particular research and 2) to allow me to use our story as part of the data to be analysed. As this research has 'me' at the very heart of it, I have adopted an autoethnographical approach to my methodology. This has been discussed in detail in a subsequent chapter.

Chapter 1
Getting Personal
Nick's and My Story

Why I am interested in my research is due to my personal and professional experiences. For the purpose of this chapter I will tell you about them and the journey I have been on and how I have arrived at wanting to do a piece of research about experiences of inclusion in a mainstream setting. As I consider my personal and professional experiences to be interwoven and co-dependent I have attempted to illustrate this by setting it out by using black text for my personal experience and green text for my professional journey. My son's story will be entwined throughout.

“Congratulations! We would like to offer you the job as class teacher” My first job was at a primary school. The school had the hearing support unit attached to it. This was the start of my interest in special education. In my first class I had two profoundly deaf children who needed a different approach for them to be able to access the curriculum. I was privileged to receive intensive training from experts in the hearing support world. I also started to get a glimpse into how a disability impacted on a family, the child and the people they encountered within the school environment.

Trying to get pregnant proved tricky. For months and months I tried and it led to nothing but me needing fertility treatment, which was successful. I will never forget the day when the radiographer cheerfully announced, "ohhhh, Mrs. Bidy you are expecting twins...wait a minute... I can see three heartbeats ...Mrs. Bidy you are expecting triplets!"

The pregnancy proved problematic leading to me being hospitalised throughout the duration.

Due to the frequency of the scans my husband and myself decided to name the babies early. We called them Rosie, Nicholas (Nick) and Tessa (Tess). After 25 weeks, during one of many routine scans, it was spotted that whilst Rosie and

Tess were thriving Nick was not. After much deliberation, heartache and professional medical advice from our consultant, Mr. Box, we decided that for the sake of the survival of Tess and Rosie we would allow Nick to naturally die in the womb rather than delivering early and running the risk of losing them all. Thankfully events took over that stopped this from happening.

Three weeks later, following another one of my many scans, on 23 December 1998, it emerged that Tess had engaged and I was going into labour. I was 28 weeks pregnant. Suddenly, everyone kicked into action as a decision was made to deliver all three babies at 2 pm on that day. A team was assembled which consisted of 15 medically trained staff. My consultant discussed the potential impact of what could happen. He warned me that he did not think Nick was strong enough to cope with the delivery and said he had a high chance of dying.

As I did not think that I would be strong enough to cope during the birth to deal with such an emotional experience I decided to have a general anesthetic. Having the anesthetic and not knowing what the outcome was going to be, was a truly frightening experience. I can remember lying on the table looking up at the anesthetist with tears trickling down my face as he tried to reassure me. On awakening I found out that all three had survived and were in intensive care in the special care baby unit; Rosie 3 lbs. 11 oz, Tess 2 lbs. 10 oz, Nick 1lb 10 oz.

All three were tiny but Nick was so small that he looked so vulnerable and fragile lying in his incubator attached to an array of wires. He was covered in downy hair with his eyes fused tightly together. It was obvious this was the start of a very long fight for him.

For months all of them needed specialist help to breath. Whilst Tess and Rosie thrived and left the hospital on the 15th February 1999, Nick was still fighting for his life.

Throughout his stay at hospital we encountered many highs and lows including receiving a phone call on New Year's Eve informing us that Nick might not make

it through the night. What I know now about Nick, which I did not know then, was just how tough and what a fighter he is. On March 18, 1999 Nick came home with an oxygen cylinder in tow.

Throughout the first year of this life we had many times in and out of hospital. We experienced things that, as a mother, you hope you never have to go through. One incident being the time when Nick stopped breathing. If I close my eyes I can picture it now; my husband holding Nick in his arms as suddenly his breathing just stopped, the au pair, Danka, running up and down the corridor shouting, " he's dead he's dead" and me frozen to the spot screaming. But yet once again Nick survived.

Over time we realised that Nick was not responding to noise. During a routine hearing screening at 6 months followed by a detailed scan under general anesthetic it was revealed that he had no hearing in the high frequencies and a significant reduction in the low frequencies. Nick was diagnosed profoundly deaf. Nick started to wear his hearing aids.

I returned to work full time at the primary school. I considered it a welcomed break from looking after the triplets! It was at this point where I had a conversation with a parent of one of the profoundly deaf children from my class. The contents of this conversation has stayed with me ever since; following the news of Nick being deaf the parent said, "be prepared for a very long fight, people really don't understand deafness." At this stage I had no idea what the parent meant, but sitting here now, reflecting, I feel exhausted from what has been an extremely long, painful, emotionally draining battle.

Nick's battle to feed, thrive, and to live continued. At his first birthday he weighed in at just over 9 pounds. This can be contributed to Nick's amazing ability to fight against the odds, his amazing strength, his perseverance and his courage. During this time we saw glints of Nick's true personality starting to develop. Even though he was so poorly his spirit was strong and positive. I have

lasting memories of hearing this uncontrollable laughing echoing around the house and realising this infectious giggle was coming from Nick.

My professional career was taking off. I applied and got a position of Deputy Head at a large middle school with the overall responsibility for SEN. My interest and passion for ensuring the best possible outcomes for those with needs was of paramount importance to me. This was driven by my own desire to ensure that others would do the best for my Nick. Whilst at this school I achieved my National Professional Qualification for Headship (NPQH) as well as setting up a nurture group for those with additional emotional and social needs.

Nick started school. His first Individual Educational Programme (IEP) had two targets that were to say the word, 'mum' and 'dad.' Nick had no spoken language. The only way he communicated was through a high pitch scream. It was the same noise a fledgling makes. This was a particular tough time as by this stage we had had 5 years of hospital appointments, operations, and people misunderstanding his deafness. One lasting memory is on Christmas Eve. We had taken the triplets to a church service. Whilst we were there Nick started communicating in the way that only he could - by screaming. Several of the congregation turned round and tutted: culminating in one asking us to control our child.

When Nick was 6 we applied for a Statement. After a gruelling fight and a lengthy appeal we got a Statement of Special Education Needs. I kept on wondering why did we have to fight so hard? Why did it go to appeal? Surely, the powers that be must have realised that Nick had no language and that he was profoundly deaf?

I was starting to realise that the way that I could make more of a difference to students with special needs was if I was Headteacher. I wanted to provide a place for students which entitled them to the very best, where parents could relax in the knowledge that their son/ daughter was being taken care of and given the best learning experience possible leading to the very best outcomes for

their child's future lives. I applied and got a Principal post of a College for students with learning difficulties. It was already judged to be an outstanding College by Ofsted.

Being a College Principal was not enough as whilst we were outstanding I realised that there were other educational provisions that were not as good. This led to me becoming an additional inspector working for Ofsted. This allowed me to inspect other specialist Colleges. I felt strongly that being an inspector would allow me to indirectly help and influence and shape practice for those with learning needs by pointing out the College's strengths and areas they needed to improve on according to the Ofsted handbook. However, the travelling and staying away from home was difficult as it was increasingly becoming obvious that Nick needed me more and more.

Nick had a difficult time at his first school as he could not speak and the teachers did not know what they were doing as they had never worked with a deaf child before. They were gorgeous people and desperately kind but did not have the skills that Nick needed. This led us to make a decision to have him educated at a resource base. One teacher, at this time, stopped and spoke to me and said, "I think I know what I am doing now with Nick." It had taken her all year to get to grip with teaching him. This decision involved Nick travelling 50 miles a day. Whilst the specialist teaching was exceptional the travelling, coupled with the lack of social interaction with the hearing children meant Nick started to struggle. After two years we decided to return Nick back to his local school against the advice from the hearing support team.

Unfortunately, the primary school did not have the facilities that I needed, so I moved to another mainstream school with a deaf unit. I was there for two years and during that period of time, my education and speech improved significantly with teaching assistants. However, I did not enjoy it there and moved back to my old school because I wanted to be around 'hearing people'. I wanted to be with my sisters as well, because I relied on them so much. The fact that I moved back to my primary school indicates that I wanted to be in a mainstream facility so that I would not have to be around other people who shared the same experiences as I did. This, consequently, also indicates that as a young deaf child, I wanted to ignore my deafness (Nick).

Back at his local school we were embraced. Nick moved from his first school to the next school. The transition was good but however problems still existed with people's attitude towards deafness and Nick's own internal struggle with his deafness. In his mind he could not justify why Rosie and Tess had no problems. It seemed that whilst being a triplet gave him strength and security it also reinforced his negative attitude towards his deaf identity. He resented them for having friends, being able to speak on the phone, singing along with Singstar on the PlayStation, talking freely, and on holiday being able to play and hear whilst swimming. He also started to struggle with the way people would think him 'silly' or 'thick', just because he spoke differently. He told us frequent stories of being in class and answering a question and being able to spot out of the corner of his eye other children nudging each other and making eye contact. His confidence hit rock bottom.

After the end of primary school, I moved to middle school, where I stayed for the whole duration of the four years. At first, I found it incredibly challenging to fit in; this was a mainstream school with more than six hundred pupils with only one deaf student. Friendship groups were forming and I struggled to make friends. I relied heavily on my sisters in class; I relied heavily on the aid of a microphone and teaching assistants. The teaching assistants would support me by writing notes and summarise what I had to do in terms of the work set. In assemblies, I would have to walk to the person giving the assembly and give the microphone; this was embarrassing with all of the pupils looking on. Once a vicar was delivering the assembly, and as I was sitting down with the rest of school, the vicar spoke into the microphone, "Hello, can you hear me?" Everyone attending assembly had heard, started sniggering and I died of embarrassment; this was just one example - I can think of many (Nick).

During a meeting with the Hearing Advisory Teacher, the Special Educational Needs Coordinator (SENCO) Nick's teachers and Nick's Learning Support Assistant (LSA), the LSA started indicating that teachers were not differentiating their work and Nick could not hear in the class; one teacher had refused to use the microphone all the time as he claimed that Nick did not need to listen to certain bits of the lesson. I was devastated. I sat in disbelief and cried. Everyone went silent and then started apologising and it was at this point that the representatives from County started to mention a specialised school. However,

later on this suggestion was withdrawn following a letter from the head teacher saying that he could meet Nick's needs.

Nick's mental health started deteriorating. Nick became withdrawn, and he had started to isolate himself from everyone. Frequently he would cry with what he considered to be the unfairness of it. He would chuck his hearing aids in the bin and sob. In his words he 'hated being deaf'.

I received counselling from Deaf Children and Mental Health Service (CAMHS) because I was not happy about being deaf and wanted to be more like 'hearing people'. I found it hard to approach new people because I was afraid of what they would think of me. I was angry about being deaf and one time, I threw both of my hearing aids in the bin. This highlighted the grievance and anger I felt because I felt I was not able to keep up with my hearing peers (Nick)

As a family we knew it was becoming critical and knew that he would have to change to a much larger school. We were concerned, how was he going to cope? Would they be able to meet his needs? Would Nick have a chance of happiness?

The advert said SENCO needed at Nick's next school. This was perfect. In my mind I could stop being a Principal, get this job and ensure that Nick and others had the best provision possible. I also knew that if it did not work I could prove to County that the school (me the SENCO) had tried everything but to no avail. It was fool proof; it would be a win, win situation. I applied and got it.

Nick transferred to the next school. Despite everything being in place that could be put into place, Nick hated it. I remember the day when Nick stood in my office, tears streaming down his face and he said 'mum, please get me out of here.' He could not stand the noise of the place, he hated the fact that he felt alone and he had no friends. He could not hear everything the teacher was saying despite the best efforts of a highly skilled Learning Support Assistant who was a touch typist and typed the majority of what was said during each session.

He did not feel 'Nick' anymore, he just felt 'deaf'. He hated the way people looked at him when he spoke. He felt different and the odd one out.

I found it hard to fit in: even more so than middle school because the school had more than fifteen hundred students. The noise was unbearable. I was in nearly the same classes as my sisters, and I received support via a microphone and a teaching assistant. I had a system with my teaching assistant via laptops; the teaching assistant would try to write whatever the teacher was saying and I would receive the information given on my laptop. Although this method of communication was helpful, I found carrying laptops and microphone around with me to classes was very cumbersome and setting up the laptops was a slow process; it was also very embarrassing.

As a result of being at college, I hated it and wanted to move to a specialist school for the deaf miles away from home. I went to see mum in her office and cried and asked her to help me. I felt that because I wanted to move to a school so far away, which meant that I had to board there, was quite significant showing that I was not enjoying my time at college (Nick).

Nick became so withdrawn and depressed at this point that he no longer felt able to go to school: so instead for four weeks he stayed at home whilst the SENCO (me) was busy arranging an emergency annual review to sort out what to do next. Thank goodness for a very close family who all rallied around to help Nick. At this stage I must point out that deaf CAMHS were brilliant and supported Nick through what was an extremely difficult and painful time for all. In addition the leadership team of the school supported us as a family. I sometime wonder if I had not been the SENCO would we have got the same support from the school and the Local Authority?

A meeting was called at County Hall. A residential deaf provision was tabled and agreed. Nick attended this meeting and talked at length about how he felt. It was a moving and powerful account and testimony to the exceptional character Nick is.

Nick moved to his new residential deaf school. Whilst I knew that it was for the right reasons, the pain a mum and father experience seeing their child move away from home was tough. It was hard for his triplet sisters who missed him dearly and felt odd without him being there. A very difficult transition occurred as Nick got used to being away from home and we got used to Nick not being there. Tears were plentiful and many reassuring phone calls between Nick and members of the family occurred.

When I moved to the new school, I was overwhelmed at the prospect of being in a total deaf environment. I hadn't really encountered this before and the fact that the deaf students were signing, although discouraged in lesson time because speaking was vital to the improvement of their speech, was like a whole new language to me.

The school has just over more than two hundred students, and each class usually consists of twelve pupils. This was very helpful to my needs, and communication was maintained via group interface headsets. I also received weekly speech therapy, which would improve my speech dramatically. Being at the school has made me develop my deaf identity, and as a result, I have formed strong friendships with my entire year group, which is made up of about twenty-five pupils. My signing skills have improved, although it isn't quite fluent as I would like it to be.

I feel that the school has brought out my gregarious side, which enables me to socialise more with people who share the same experiences. This has made my confidence grow and I am not shy in approaching people and talking in social situations such as parties like I was before, although I will nearly always struggle to hear them and ask them to repeat most of the time. As a result of being more confident, I was invited by a friend to go skiing, which boosted my confidence of being deaf even more.

I have been discharged from counselling as I don't need it anymore. This was because it was evident that I was embracing my deafness and was more confident about making friends. This is something I probably would never have achieved had I not embraced my deafness; the fact that I am at the specialist school has enabled me to achieve my full potential and in areas I thought would not ever have been possible back then (Nick).

Nick was happy and so I was happy. It was time to move on from being a SENCO. I needed more and to carry on my drive to help improve special needs provision and choice for learners and families. I am currently Director of Colleges helping

Colleges across the country to achieve high standards of education and care and helping to spread the word of their existence so parents do have a choice

Looking back I did not realise how much I was affected by what had happened to Nick. It was only when he became happy and content at his residential school that I realised that I had stopped worrying, I had stopped being so weepy, I had stopped feeling so much pain. Now I talk with upmost confidence about Nick's positive future; life is good.

It is our story that has driven me to ask what have been other people's experiences in a mainstream education setting.

Chapter 2
Methodology Section

An Autoethnographical Approach.

The intention of this section is to describe the methodology that has been used to gain an answer to my research question. Within this section I will explore how I defined my research question, my reasons for choosing a qualitative auto-ethnographical approach, a description of the study setting, a study sample, and my data collection methods and the process I went through. This section is underpinned by ethical considerations.

Defining my Question.

First of all I had to define, 'what was my purpose? What did I want to find out?' To me the question was equally as important as the autoethnographical methodology that I had chosen as I knew that I had a story to tell and that I wanted that to be an integral part of my research. I could not ignore the 'me' in this work. Nick's and my story clearly demonstrate this. Richardson's (2001) work reminds us that it does not matter how much we try to take ourselves out of our writing; we are always there, especially when an experience has had a dramatic effect on someone's lived world. This approach is in contrast to Thomas' work where he considers the methodology to be secondary, 'you must put the question before the method and let the question determine the method you use to answer it' (Thomas, 2011:27). After much deliberation I came up with my initial research question:

'Does attending a specialist further education college for young adults with intellectual disabilities promote inclusion?'

I soon became aware that my research question was not fixed in concrete. Thomas (2011) considers the initial question to be a 'prima facie' question; a not very well thought out question. His work suggests that the question proceeds and develops from a prima facie question to one that is more refined and final. Initially, I remember when I realised that the question was not fit for purpose and that it did not get to the crux of what I wanted to explore, I was afraid to change it. I recall going to see my supervisor and explaining my concerns. I was nervous and anxious because I felt as if I was actually starting from scratch again

but after discussions and more reading I soon came to realise that this was in fact part of the research process; and it was an important part. I was not starting from the beginning but what I was actually doing was developing my epistemological position and allowing my autoethnographical approach to be developed. From reading, listening and talking to others it helped me redefine what I understood. It helped me to reformulate, and rethink (Stake, 1995). This was enhanced and further developed through my literature review and writing my own story as it gave me a wealth of information: a treasure trove from where nuggets of gold could be mined. This development made me shape my learning and thought processes as it helped me to redirect my work and to crystallise my research question. Parlett and Hamilton (1987) recognised the benefits of this and the need for changing your research question. This recursive approach by going back and forth and rethinking was absolutely necessary. It led me to change my focus from seeing inclusion through a specialist lens to seeing it through a mainstream perspective: as the majority of students with profound special needs attend mainstream school and colleges before a specialised provider is considered and this is where my own story started. The ability to attend a specialist school is usually dependent on the child having a Statement of Special Educational Need. Out of the 1,492,950 pupils who have been identified as having SEN only 232,190, (DFE, 2014) have a Statement of Special Educational Needs. 53% of those with SEN with a Statement attend a mainstream school in comparison to 41.4% who attend a specialist school (DFE, 2013:6). This data would confirm that the significant majority of those with SEN with or without a Statement attend a mainstream school setting. I felt my initial question had raced ahead and had ignored the fundamental philosophical and political theories and practice that surround inclusion for the majority in today's English education system. It also ignored my starting point. My new question was formulated,

'What does inclusion mean for parents with children that have special educational needs and what does it mean for the children themselves in today's mainstream schooling system?'

It felt right and more appropriate and relevant with what was happening in today's society. It also resonated with my own experiences.

Using an autoethnographical approach to my research.

I used an autoethnographical approach to my research, as I needed a framework that would give value to my desire to make sense of my own experience of inclusion at mainstream schools as a parent and a professional. As a researcher I was not trying to become an insider in the research setting, I was in fact already 'an insider'. I had a child with special needs who had gone through a mainstream system before going to a residential school for the deaf. Being 'an insider' has received heavy criticism. Autoethnography at home can be seen as a 'deterrent to objective perception and analysis' (Aguilar, 1981:15). When you're an insider you can be seen as too familiar within the setting and maybe being an outsider allows you to read what is going on with more objectivity, as you are more detached and more distant. Cheater (1987) describes auto-ethnographical research, 'As being in your own front room' (Cheater, 1987:122) I needed to confront my own role and stand back and see the impact an insider can have. This will be discussed later. However, like many defenders of the insider as a researcher I can see multiple benefits, (Hennigh, 1981, Ellis and Bochner, 2006 and Vickers, 2010). Outsiders can be seen as less trustworthy, less discerning, lacking commitment to the 'group' and having no political or personal axe to grind. Insiders, debatably, blend in more easily, Anderson (2006). I knew that I did. Arguably, insiders find building a rapport easier due to them having more linguistic competence surrounding the area under study and therefore having more capital, (Bourdieu, 1996). Research participants are more likely to open up with an insider as outsiders can be perceived as strange and alien to their world:

Insiders have greater access, has negotiated entry to a range of settings and people, knows who to ask, can interpret responses more subtly, can more easily gain knowledge, furthermore the research is more ethical as

opposed to a token membership of an outsider (Hennigh, 1981:24).

Being an insider or outsider can both be seen for their positives and negatives. Both must acknowledge the impact that they could potentially have especially when considering 'objectivity':

The outsider must to some extent get in to the native heads, skins or shoes, whereas the insider must get out of his or her own (Aguilar, 1981:24).

Through autoethnography I got a chance to tell my own story, to externalise my inner dialogue and to start to make sense of my unique world experiences (Russel, 1998) by using a systematic reflection and a scholarly approach. It has allowed me to make sense of and discover new knowledge. My initial supervisor warned me against using this approach as it was considered 'too radical', and a 'risk'. Looking back now I am so glad I did. However, throughout this method I have been critiqued for being 'too colloquial' or 'too chatty' when the very methodological approach that I have chosen promotes this freedom as by writing in this style it allows the reader to better understand 'me'. I make no apologies for it. My approach will not dilute the value of this research through a social science lens:

Students will not lose the language of science when they learn to write in other ways any more than those who learn a second language lose their first. Rather, acquiring a second language gains them entry into a new culture and literature and it leads them to a deepened understanding of their first language (Richardson, 2000a: 924).

This approach combined with using other people's stories has enabled me to confirm or triangulate my own multi-layered views. So in part it is ethnographic, where I have used stories of others in order to gain knowledge of a group's experience, and part autobiographic, where I have reflected on my own experiences. As according to Marechal,

autoethnography is a form of research that involves self-observation and reflexive investigation in the context of ethnographic field of work and writing (2010: 43).

For the purpose of this research project I saw autoethnography as a form of ethnography. The definition of autoethnography lies very much with the researcher's interpretation. In other words as Ellingson and Ellis (2008) put it, 'Whether we call a piece of work an autoethnography or an ethnography depends as much on the claims made by authors' (2008:449). This is echoed in anthropologist Deborah Reed-Danahay's work in (1997), she said that 'either a self- (auto) ethnography or an autobiographical (auto) ethnography can be signaled by autoethnography' (1997: 2). It has numerous definitions attached to it. For me it was using my own biography (auto) to relate to others in the same 'group' (ethnology) i.e. parent of a child with profound needs wanting to make sense of the inclusion culture. This approach to my research has been influenced by my own biographical account. My own personal account, clearly showed why I wanted to investigate inclusion through the eyes of the parents and students. The essential difference between ethnography and autoethnography is that in an autoethnography, the researcher is not trying to become an insider in the research setting. He or she, in fact, is the insider. The context is his or her own. Through autoethnography, those marginalised individuals who might typically have been the exotic subject of more traditional ethnographies have the chance to tell their own stories (Russel, 1998).

The approach that I am taking, part autoethnographical and part ethnographical can be better explained with the use of Anderson's work, 2006. He used the term, 'analytical autoethnography'. Anderson, 2006, promoted this analytical autoethnographic paradigm as an alternative approach to autoethnography that was promoted by Ellis and Bochner, 2006. Anderson veers towards incorporating aspects of autoethnography into analytical ethnographic practice in order to make sense of a social phenomenon. This was important in my research as I wanted to ensure that meanings, and a better understanding of what it meant to be included in mainstream schools for parents and children in today's society arose from the stories told.

Ellis and Bochner (2006) contested Anderson's work as they felt by encouraging an analytical approach towards autoethnography that he wanted to control it, to

create logic, to analyse it, to freeze culture where they considered autoethnography important to see culture in motion, where creative narratives arise, which do not need analysing, narratives which were unruly, vulnerable and rebellious. Ellis and Bochner (2006) were worried that autoethnography seen through Anderson's eyes would tame and dilute it and make it lose its identity by turning it into mainstream ethnography in a bid to theorise and generalise it.

One would become a detached spectator- I become only a head, cut off from my body and emotions.....
Caring and improvising is for us what abstract and controlling is for them. We want to dwell in the flux of lived experience; they want to appropriate lived experience for the purpose of abstracting something they call knowledge or theory (Ellis and Bochner, 2006:431).

I agree with Ellis and Bochner that caring and improvising is important as personal stories are a 'gift of living testimony' (2006:430) but also it is essential to have a framework from which autoethnographical findings can be analysed and made sense of. I do not believe it dilutes the epistemological stance in fact I feel it enhances it. One does not need to lose the passion and emotion that Ellis and Bochner promote (2006) but instead that passion and emotion needs to be captured. Stories that make you feel that it is hard to think about anything else are crucial to this. My aim was to use their purist approach coupled with using empirical data to gain insight into a broader set of social phenomena than those provided by the data themselves.

My method that I wanted to use resonated with Anderson's analytical methodology (2006). There were aspects of his work that I considered important to my autoethnographical approach. The first was his notion of complete membership as a researcher (CMR): as I am a complete member of the social world that was under study. Being a CMR has given me the insider's status that I touched upon before. CMRs 'come closest of all to approximating the emotional stance of the people they study,' (Adler and Adler, 1987:67). However, being a CMR does not stop you from encountering problems. Throughout this research I struggled with an identity problem as not only was I

a complete member of the group that I was studying but also I was a researcher and professional within the field of SEN. This separated me from the other group members. Arguably, making me less of a complete member? The other group members may have lived more complete in the moment unlike me who had multiple foci. Merton termed it, 'the ultimate participant in a dual participant observer role' (1988:18). Being in my role as a researcher created tensions and conflict as whilst it was helpful to gain direct access to values, beliefs and experiences it also limited my access to others. An example was when a parent stopped in her tracks when she started to reveal something that she did not want recorded. If it had just been me as a parent talking, I feel confident that she would have carried on. Marti, (2005) autoethnographical study as a lay Pastor was fraught with conflict as on one hand the congregation wanted to speak to him in confidence as a Pastor, yet on the other hand he encountered people talking in a guarded way for his research.

The second aspect of Anderson's (2006) work that was important in my autoethnographical approach was his notion of analytical reflexivity. I interpret it as reflexivity showing an awareness of reciprocal influences between the researcher and the storytellers, 'reflexivity expresses researchers awareness of the necessary connections to the research situation and hence their effect upon it and the impact on them' (Davies 1999: 7). Atkinson, Coffery, and Delamont (2003: 62) observed and saw that the autoethnographers become part of other people stories,

Autoethnographic as authors frames their accounts with personal reflexive views of the self. Their ethnographic data is situated within their personal experience and sense making. They themselves form part of the representational processes in which they are engaging and are part of the story they are telling.

As a CMR, as opposed to more detached observer, I was right in the thick of it, and my interrogation of 'self' and others transformed my own beliefs, actions and sense of self. Murphy's (1987) and Schwalbe 's (1996a) work both capture the impact the study has on a researcher:

Every insight uses both a doorway and a mirror as a way to see their experience and the way to look back at mine (Schwalbe,1996a :58).

Anderson's, 2006, use of the analytical reflexivity was very appealing to me, as I knew my thoughts were shaped on the journey that I had encountered. The decisions I have made in order to represent and frame certain aspects have all been funnelled through analytical reflexivity; this has been further enhanced due to the time that it has taken me to write this thesis. I am not the same person now as I was when I started.

An autoethnographical approach is not just about 'me' and 'self' but I see it as an interrelationship between researcher and other storytellers. It is these interactions that not only shape thoughts, feelings and values but also allows the researcher to go beyond the subjective (Davis 1999, Anderson 2006). So in this way it becomes a relational activity, (Ellis and Rawicki, 2013) unlike the autoethnographical approach of Ellis and Bochner, 2006, where there focus is firmly on the subjective experience; where links should not be made between stories but instead seeing each one seen as a unique story to be told not to be analysed. Ellis and Bochner use Arendt's (1973) conception of storytelling to make this point, 'storytelling as an activity reveals meaning without committing the error of defining it' (Arendt, 1973:107). This would suggest that Anderson (2006) by trying to generalise and make sense of the stories told was always trying to reach a conclusion rather than seeing each story as a conversation to encourage multiple perspectives, unsettled meanings and plural voices:

If you transform the story into another language, the language of generalisation and analysis, you lose the very qualities that make a story a story you want to protect the integrity of the story and not close off the conversation and the engagement with it (Bochner and Ellis 2006:440).

What I am doing is using each story to try to have a better understanding of the world we are experiencing. I am trying to promote conversation. I am not ignoring the multiple perspectives and voices that come from stories but I am trying to shine a spot light on some aspects to help us better understand what people have gone through. As Ellis and Bochner (2006) feel if you try to analyse

the story you sacrifice a story at the altar for traditional sociological rigour; so a preference for analysis means missing the narrative point- the importance of the story, the plot, and characters; seeing the theory as superior to story. Seeing my work through an analytical autoethnographic perspective not only promotes an emotional response by keeping true to the narrative, the plot and the characters but it uses empirical data to try to gain insight into a social phenomena. I am not content to understand just what is going on in someone's life but I have a desire to make sense of it by making generalisations; capturing and helping to understand what is going on,

The value and vitality of a piece of research depends on it providing a theoretical elimination of the topic under investigation (Karp, 1996:14).

I reject Ellis and Bochner's limiting views of autoethnography.

The last aspect of Anderson's work that I consider central to autoethnography is the need for the researcher to be highly visible and active in the text. The researcher's own feelings and experiences should be incorporated into the story and should be considered a vital aspect of the data to help understand what is being observed. Furthermore, Anderson, (2006) argues that one should document the changes in beliefs and values over the course of the fieldwork,

vividly revealing themselves as people grappling with issues relevant to membership and participation which is fluid rather than seen in a static social world (Anderson, 2006:384).

The researcher should not shy away from how we feel. One must textually acknowledge ways in which the researcher's participation reproduces and transforms social understandings and relations. This is echoed in Davies' work, 1995:

to seek to develop forms of research that fully acknowledge and utilize subjective experience as an intrinsic part of research (Davies 1995:5).

However, caution must be exercised, as there is a danger that high visibility can lead to the researcher becoming too self-absorbed. Geertz refers to it as 'author saturated text' (Geertz, 1988:28). Arguably, autoethnographic approaches can lose their sociological offer when they become too self-absorbed and take too much interest in ornamental decoration. It is important to recognise the need to take the reader to depths of personal feeling, to help the reader understand the emotion but it is equally as important to make sure that it does not come too self obsessed. Reading Ellis and Bochner's response to Anderson's paper, 2006 highlights the unnecessary decorative embellishment that they used to tell their story: 'Art (Arthur Bochner) runs his fingers through his hair, holding on to the end as though he is trying to pull an idea out of his head' (Ellis and Bochner, 2006: 438). The exposure of the 'self' who is also a spectator has to take us somewhere we could not otherwise get to but it has to be essential to the argument, 'not decorative flourish, not exposure for its own sake' (Behar, 1996: 14). It was important to avoid self absorbed digression to make sure that I did not lose sight of the study, (Rosalado,1993):

We must not lose sight of the ethnographic imperative that we are seeking to understand and make sense of our complex social world of which we are only a small part (Atkinson, Coffrey and Delamont 2003:57).

Interestingly, Ellis and Bochner (2006) state 'Just because we're presenting the author in the text it doesn't mean it becomes an autoethnographical piece of research' (Bochner, 2006:431). As they promote autoethnography as far more than just the author it is about each story being an evocative piece of work in its own right.

I have written about my experience in my personal story and it is woven throughout this thesis. This coupled with the other stories highlighted questions on the inclusion experience that I wished to explore. My writing in particular was about critical incidences/epiphanies, which have had a significant impact on the trajectory of my life and others. These times have forced me to reflect and analyse these lived experiences as Zander and Zander (2000) point out that my

life after these experiences was never the same. It was transformative, even after the event. This reinforces the importance of analytical reflexivity in Anderson's work (2006). Transforming is on going and reflexive after every lived second:

Intense situations and effects that linger - recollections, memories, images and feelings- long after a crucial incident is supposedly finished (Bochner, 1984: 595).

From the questions that have arisen from my own personal experience I have then analysed the culture that surrounds inclusion within a mainstream environment: the values and beliefs. I have sought shared experiences and commonalities from cultural members (insiders) to better understand the inclusion culture (Maso, 2001). As I have previously stated I felt it important to apply rigour and an analytical approach to my research as well as just telling stories and to:

“Look at experience analytically. Otherwise you're telling your story and that's nice but people do that on Oprah a US based television programme every day. What makes your story more valid than anyone else's? What make your story more founded is that you are a researcher. You have a set of theoretical and methodological tools and the research literature to use. That's your advantage. If you cannot frame it around these tools and literature and just frame it as my story then why or how should I privilege your story over anyone else's I see 25 times a day on TV?”
(Mitch Allen, 2006, personal interview with Oprah Winfrey, May 4th USA)

I have taken the first person narrative approach to my research as I have personally experienced an 'eyewitness account' (Cauley, 2008) of inclusion as a parent of a child with profound special needs. When I am using the accounts from the storytellers, I have used both the second and third person narrative appropriately. This will help the reader; both 'insiders' and 'outsiders' to better understand my thesis.

The next section will discuss the process used to gain the stories.

The process used to gain the stories.

Study setting

This study was set in a rural part of North England. The parents, who took part in this study, all had children who had been identified by the school system as having 'Special Educational Needs, (SEN)'. All of the children who were involved in this study had attended the local schools.

Study sample

For the purpose of this research a sample of 10 participants, whom I call storytellers, were used; 5 parents, me being one of them, and their respective children were interviewed. In qualitative studies samples are typically small. Whitehead and Anell's (2007) work, cited in Birks and Mills (2010), suggest that in a qualitative study the common range of participants is between eight and fifteen. Even though the sample size appears small it is highly appropriate, as each one gave detailed accounts of their experiences of inclusion in the mainstream schooling system. My research can be accused of using too few cultural members (Anderson, 2006) but as I have pointed out earlier the storytellers in my research, whilst small, have given me very detailed accounts from which detailed analysis can occur. My goal has always been to produce an analytical, accessible text that changes the world we live in for the better (Hollman Jones, 2005). To achieve this outcome, quality is far more preferable than quantity and this will allow the storytellers to make sense of themselves and their own experiences.

My research examined the journey a parent embarks on when they have a child with SEN attending a school that is in the mainstream system. Quite simply, I

asked the parents to tell me their story and experience of mainstream schooling. I then asked each parent's child the same question to obtain their views on their experience.

I then examined the critical incidents, which emerged and are still occurring for some. I then examined positive incidents and negative incidents, identifying themed commonalities or exceptional experiences: both subtle and obvious (Welch *et al*, 2011). Comparisons of this data enabled me to further explore commonalities and exceptions, alongside differences and similarities in parents and children's accounts, which have led to increased validity.

Deciding who to include in my research was fundamental as the outcomes affected and underpinned the whole research process, Parahoo (2006). Careful selection of my storytellers was vital as their stories allowed me, the researcher, to make generalisations without having to examine every member of the UK population. I will discuss generalisations later. As a sample has been described in Polit and Beck's (2010) work as a portion of the population chosen to represent the larger voice.

The storytellers had been chosen for very specific reasons; all of the parents had children who had special educational needs; all had been through the mainstream school system and most importantly the parents and the children wanted to share their stories.

- Nick has a hearing impairment
- John has autism
- Archie has Attention Deficit Hyperactivity Disorder (ADHD) and Asperger's Syndrome
- Frankie has autism and
- Ian has been diagnosed with autism.

In the next chapter I will consider what constitutes a 'need'.

It was imperative to consider ethical issues throughout this process of my research because of the 'complexities of researching private lives and placing accounts in the public arena' (Birch *et al*, 2002:1). The issues go beyond just the interview and are embedded in all stages from thematizing to reporting. It was important to remember that the ethical guidelines produced by the University of the West of England serve to ensure a consistent ethical code of conduct as does the British Educational Research Association, (BERA 2011) ethical guidelines; arguably they can actually serve as a new conservatism constraining qualitative research. Lincoln (2005) spoke of a danger that trying to adhere to the ethical code can be cumbersome and time consuming and most importantly restrictive. Birch *et al* agree and state that there is an:

Inherent tension in qualitative research is characterised by fluidity and inductive uncertainty and ethical guidelines that are static and increasingly formalized (2002: 2).

However, making my work ethical underpinned everything. I will now describe the process that I went through to gain the stories.

The Process underpinned by ethical considerations.

Firstly, I made sure that each storyteller gave consent.

To achieve informed consent it was vital to address three elements to ensure I kept my work ethical: capacity, information and voluntariness.

Capacity. Capacity is defined as the ability to retain knowledge, and the authority or legal qualification to perform an act. I had to ask myself, 'Were the storytellers able to decide if they can participate?' This was particularly important for my research, as 5 out of the 10 participants were students with special needs. Working alongside the parents and having the knowledge of each child we considered all to have capacity in accordance with The Mental Capacity Act, 2005. Following the British Educational Research Association Ethical Guidelines, (BERA, 2011) and National Children's Bureau, (NCB), Guidelines for Research with Children and Young People, (2011), was central as both

documents highlighted the right of the child to speak and express their views freely in accordance to Article 12, of the United Nations Conventions on the rights of the child, 1989. All children wanted to take part and tell their story; all had capacity to do so.

As the students were minors I sought written consent from the parents as well as from the students: again a recommendation from NCB, 2011 where they endorse parental consent for under 16 year olds.

Information. All that took part were fully briefed about topic of the research - the purpose and the procedure of the research project. This included:

- The aim of the project
- The type of data that I was collecting
- How I was collecting the data
- Confidentiality
- As I was working with under 16s the protocols surrounding child protection and disclosure
- The time commitment expected from the storytellers
- The right to decline to offer any particular information requested by the researcher
- The opportunity to withdraw from the study at any time with no adverse consequences
- Details of any risks associated with participation
- How the data would be used and planned outcomes
- How the results of the research will be made available to participants

- The opportunity to read and change what is written about their experience.

Please see Appendix 1 and 2.

In order to ensure that this was fully communicated to the storytellers my initial meeting discussed the above. When I met them again I reminded them.

Voluntarily. All participants joined in of their own free will. I sought written 'free consent'. The question of what is free consent must be challenged as by the sheer nature of me asking someone to take part to be interviewed am I in fact coercing him or her to take part? (Stake, 2004) I also informed the participants of their right to withdraw at any moment. This was necessary to repeat so that I felt as though I gave the storytellers multiple opportunities to withdraw.

The question of privacy went through the entire process.

The question of what is public and what is private was difficult to answer. Even when someone has agreed to be interviewed and to share their story they might not fully understand that the knowledge I have constructed from our interview will be shared in a public arena. It was important therefore that I fully briefed the participants beforehand and also let them see a draft of what I intended to publish. This process occurred several times. As social research, 'Entails the possibility of destroying privacy and autonomy of the individual', (Barnes, 1979: 22). If the participant was not fully involved and informed then it could have been seen that:

When they do not own the data being furnished about themselves, they have been robbed of some essential element of dignity. In addition to having been abandoned in harm's way (Lincoln and Guba, 1984: 236).

How often were the storytellers interviewed?

The first time was to tell their story, the second time was to read and check what

I had written. The third was re-reading their work in accordance to the changes that they had requested. However, we had a pre-meeting to discuss my research and the process to ensure that they fully understood what was going to happen and their involvement. I then gave them time to reflect before the first meeting to ensure that they wanted to continue.

Creating the right environment.

In order to help build the stories it was of fundamental importance to create a non-judgmental environment where a sense of equality existed between us. I wanted to empower the narrator to tell their story. For this reason I felt it necessary to hold the interviews at the storytellers' houses, in their own familiar surroundings. This gave them the security that they needed to be able to talk freely without feeling intimidated by a new environment. This was particularly important for the children. Connelly and Clandinin's (1990) work suggests that the ideal, when trying to achieve effective research is where a sense of equality is reached between the interviewer and the storyteller. By using the home environment it allowed us to reach a joint inter-subjective understanding of the stories that unfolded.

Creating the right environment extended to consider both verbal and non-verbal approaches, both equally important in creating positive relationships. I considered my eye contact, how I was sitting, my facial expressions and tone of voice throughout the interviews as I was aware that my body language and how I spoke had an effect on the type of relationship that existed between the storyteller and me. It was a very positive relationship- each person talked freely and openly.

I had to listen carefully to what was being said and know how little or often I needed to interject.

When I was interviewing I was always mindful that I could create an interactive produced meaning from the interview itself. As whilst the focus was on the participant about his or her story I was careful that I did not give an emotional response to the interview and knowledge of what was being discussed as this could have lead me personally to reflect and add context and layers about the story that was being told (Ellis, 2004) and could potentially change the 'truths':

A layered approach alongside abstract analysis and relevant literature will frame a source of questions and comparisons rather than seeking outcomes of 'truths' (Charmaz, 1983: 117).

I had to guard against interjecting too much and quickly developed the art of wistful listening but with well thought out responses and questions to clarify what was being told.

Many researchers such as Mayo (1933), who conducted the Hawthorn study, felt it necessary to remain completely objective and dispassionate whilst conducting their field research. He trained the interviewers to just listen and not to interrupt or give advice as he wanted to, 'ensure they avoided anything that might put an end to free expression in an individual instance' (Mayo, 1933: 28). However, in sharp contrast Bourdieu, states that interviews are not merely,

Tape recording sociologies but should be actively following up on the subject's answers, seeking to clarify and extend the interview's statements in order to gain knowledge (1999: 64-65).

Bourdieu's thinking resonates with my thoughts and the way that I conducted the interviews. I, like Bourdieu, considered it important to contribute to the interview but at the same time recognising the importance of not influencing the storyteller's own point of view. It was essential to give the storyteller time to talk, as Sennett reminds us, 'the craft consists in calibrating social distances without making the subject feel like an insect under the microscope' (2004, P34). I wanted to 'feel' the story and make the teller feel as comfortable as possible. The art of asking second questions was significant and relied on active listening on my part. Decisions about which of the many dimensions of the answers were important to pursue required my knowledge of the interview

theme and the sensitivity of the social relationship of the interview. Dreyfus and Dreyfus (1986) work highlights the interviewer having intuitive skills where you become attentive to situational cues, which help the story to develop in a meaningful way. This meant that throughout my interviewing I had to have flexibility. In addition the storyteller sometimes went off at a tangent, it was therefore important for me to develop skills of being able to reassign the storyteller back to the story if I considered the narrative episode not complete in that particular turn. Sacks (1992) describes this as his; 'Assignment Theorem' where to be able to do this you need to understand when a narrative unit ends and also what it is that is considered to be reportable. I consider his approach as injecting a little bit of objectivity into the storyteller's social situation.

However, it was imperative that I did not wander away from a position of curiosity. I had to be vigilant against my own prejudices, beliefs and value systems. In addition I had to recognise that individual perspectives on experiences changes as one encounters new experiences and dialogues with others. I knew that just by being present and asking a few questions it would create a new experience and the dialogue that they had with me could be perceived as influencing the storyteller's version of events and consequently the story what was being told; indicating that a narrative is continually being constructed and revised and the original narrative has been changed over time. This also suggests, which I think is a very important point, is that a multitude of voices are present within one's individual story.

The most noteworthy part of the process was the importance of retellings.

Retellings and re-drafting

Each person was able to read and redraft their transcript of their interview. I gave them time to process what they were reading. This was critical as I felt as though they had charged me with a very important job of looking after their very private information; I did not want to do them a disservice by representing their information in the wrong way. By doing this it allowed for reflexivity and gave

the participants a chance to add elements to the story (Richardson, 2001). It allowed for my writing to be co-produced and it was highly sensitive to the participant's feelings. Ellis's work highlights the importance of always recognising the storytellers feelings and valuing them as humans rather than just seeing them as informants (2001). My writing became a social process where I was not only able to respond to the literacy changes but also the participant's physical reactions when they were reading it, for example Mandy started nodding violently when reading one section of the work about the lack of understanding of one teacher. I asked her if the section was ok or could it be enhanced to reflect Mandy's feelings? We enhanced it.

A particular concern that I had to guard against was the danger of the more a story is told the less credible it can become. Arguably, by me encouraging the storyteller to comment on the draft piece I could have been diluting the knowledge that was constructed at the time.

In addition an ethical consideration is that memory is fallible and can affect the truth, (Tullis *et al*, 2009) it was important to consider credibility in terms of what Phillips (1997) described as a 'reporting paradox'. In other words the more you report an event the less credible it becomes as it becomes further shaped by the teller. This was significant to understand that a story can become distorted and less credible the more times it is told others would say the more time it is told the more credible it becomes, (Griffiths and MacLeod, 2007).

Getting the most out of the storytellers.

All parents and three of the children were completely happy and able just to talk about their experience and were able to sequence it in time order. However, for two children they needed points of reference to be able to jog their memory. So, I created an A3 brainstorming map with pictures of their school logos from where they started to now with pictures of them at the respective schools; given to me by the parents.

This was very effective as by presenting pictures it enabled them to make sense of and make a connection to each experience. It enabled each storyteller to search his or her own reservoir of experiences and knowledge in order to make sense of the image presented. The danger that I had to guard against was that presenting an image can sometimes provoke a desired response. Goffman in 1956 in his book on behaviours describes a man tripping over a pavement stone and instantly looking up to see who had seen him out of embarrassment and humiliation; a desired response. In addition the same picture can provoke a different response from different people. One picture, which I shared with Nick, was a school photo of him as a smiling, happy-go lucky child when he was 8 years younger. He instantly recounted times of happiness. However, subsequently, I recounted the same episode but remembered it as a desperately unhappy time. So it is important to go beyond the image, beyond the illustration and allow the storyteller to get 'inside the question' (Flyvbjerg, 2006:223). Pictures, however, can serve as a prompt.

During the process I had to guard against getting too close to the storytellers.

Ethical issues affiliated with friendship were a very important part of my process. As it was very hard not to get too close to the storytellers as what they shared were highly personal and highly emotive experiences, and one that I had great empathy with, (Tillmann, 2009). In addition, in my professional capacity I already knew the people who were taking part in my research. I valued the interpersonal ties that I already had with them. It was a balancing act between ensuring they felt close enough to me to share such personal accounts but yet on the other hand it was important for them to have the clear understanding that I was there as a researcher. As to them I could have been perceived as having multiple roles; a teacher, a professional, a friend, a parent and a researcher and therefore it could have been tricky for them to separate one from the other.

Ethical issues surrounding friendships formed a crucial aspect of my research and 'I considered it at all times' (Ellis, 2000: 725). The storyteller might have

disclosed some experiences that they would have preferred to keep to themselves - where the interviewer goes where they are not invited. Foucault expands on this point and gives some ethical advice: 'my point is not that everything is bad, but that everything is dangerous' (1997:56). I was mindful that by forming close relationships with the storytellers; making it too familiar and too comfortable, they might say something that they might later regret. However, it was not necessary to read them a social equivalent of a police caution... 'Anything you say or do maybe taken down and used as data...' but it was important to remember this point throughout this process.

Burman (1997) work also reminds us of the dangers that relationships can have especially when an interviewer's show of intimacy may involve faking friendship (Dunscombe and Jessop, 2002) and obtaining information falsely. This can be ethically questionable. It is important not to fool the storyteller by pretending to accept and agree with their views being made, (Taylor, 1991). To help me to overcome some of these issues I injected objectivity to the research process so that I minimised the risk of getting too close. For example, I gave set times to the interview process and made sure that I did not ask any questions which could be seen as leading them down a pathway that I wanted them to go or to nod in the right places when I wanted to know more. It was hard at times to keep impartial as a big part of me wanted to scream out, 'I experienced that too'. I had to ensure that no one felt exploited throughout the process. That would be ethically wrong. Beynon, 1983:47 described it as 'just fodder for research', (47), I endeavoured to empower them to become part of the research process and feel a co- author of their bit. The danger of autoethnography is that it can become a 'deterrent to objective perception and analysis' (Aguilar, 1981:15). When you are an insider you can be seen as being too familiar within the setting, being an outsider may allow you to read what is going on with more objectivity as you are less detached and more distant, Cheater (1987). However, insiders arguably are less likely to generalise and stereotype as they have lived the experience and see each experience as unique. Insiders, arguably, hold more capital in the eyes of the storytellers as they have more knowledge surrounding the area under investigation:

Insiders have greater access, has negotiated entry to a range of settings and people, knows who to ask, can interpret responses more subtly, can more easily gain knowledge, furthermore the research is more ethical as opposed to a token membership of an outsider (Henning, 1981:24).

Being an insider or outsider can both be seen for their positives and negatives. Both must acknowledge their own impact they can have on losing objectivity, (Aguilar, 1981). As an insider it was important to guard against getting too close to the other storytellers.

During two of the interviews, parents cried.

When I embarked on this process I always knew that I was walking into territory that was highly emotive and provoked feelings and emotions for the storytellers. I was very mindful that when parents speak about their child's experiences it could be sometimes joyful, yet sometimes immensely painful. This, I believe, after having many years as a SEN professional and a parent, is perfectly normal and something that we should not shy away from or feel embarrassed if it happens. However, I had to guard against harm as a serious ethical consideration. Research can cause stress and can make the storyteller relive emotions that had previously been controlled or unexposed. In addition by bringing up memories you may end up framing it within a new discourse as you are seeing the memory through time and space as it is today.

As a researcher I kept on asking myself what effect was my research going to have on the health of the person that I was researching? (Glaser and Strauss, 1968). The question of harm is of paramount importance for several reasons:

- My research involved (vulnerable) students who were under 16.
- My research involved a sensitive topic, which has a real impact on lived lives.
- My research involved access to highly personal information

I minimised the risk by managing the potential dangers. BERA, (2011), ethical guidelines clearly highlight the importance of taking all the necessary steps to reduce intrusion and to desist immediately if there is a sense that my actions may have caused emotional or other harm. By spotting when I was entering territory that was causing pain, being extra vigilant with the storyteller's body language and listening extra carefully to what was being said, and knowing when to stop was critical.

On two occasions, two different parents cried. In both cases I stopped the research process just for a few moments to allow the parents to compose themselves. I asked if they wanted to carry on and both said, 'yes'. I later asked them both about what caused them to cry. Both spoke of the immense frustration they felt and the exhaustion of feeling as though they were fighting all the time; both exclaimed I always do this when I speak about my child. I therefore felt it important to ask myself at what point does the experience become harmful? In my professional career I know that when I speak to parents who have encountered difficult times for their child it is not uncommon for the mum to cry when recounting it. I know as a mum myself that when recounting the experiences I have had with Nick I have cried. ... and still do. Even reading Nick's and my story causes tears to come to my eyes. Is this harmful? I would say no, it's normal and completely acceptable. Smith (1999) wrote about the potential therapeutic benefits of participants' reviving unpleasant memories. Morse (1994) identified the benefits as catharsis, self- acknowledgment, sense of purpose, self-awareness, empowerment, healing, and providing a voice for the disenfranchised. Throughout the research I had anticipated the mums crying. However, if it had become apparent that the experience had exposed great emotional problems or needs which require professional help I would have ensured that the storytelling and the session would have stopped. This never happened. In addition working with children I followed the guidelines from NCB where they recommend that I had contact details of professional people who could help if they found the experience too much.

If the research has involved discussion of painful or difficult experiences,

the researcher should ensure that the child takes details of support services away with them (NCB, 2011:34).

Being aware of the vulnerability of the participants and the sensitive story they were telling was morally and ethically correct.

As the researcher I was careful not to absorb the emotions and cause myself any harm. Being extra vigilant to my own needs seemed sensible. I cannot pretend that I did not absorb many of the experiences that were told and related them to my own and the pain that I had felt. But what it did do was keep on reminding me why this autoethnographical approach was so necessary.

The stories told had to be guarded against implicating others.

As well as the possible psychological harm I was careful not to do anything that could potentially damage a reputation of the location, the schools or individuals. I did not want to expose anyone. By default when we tell our stories we implicate others in our work. For instance, when I recounted the story of my own son it was difficult to mask others who have touched his life without altering the meaning and purpose (Adams, 2006; Etherington, 2007; Trahar, 2009). We do not live in isolation; social networks connect us all. That is why the question of relational ethics in autoethnographical research is so important, (Ellis and Rawicki, 2013). The danger is that by using personal experiences in this type of fieldwork not only does the storytellers implicate themselves but also others (Trahar, 2009). To help overcome this issue, as I have previously highlighted, I let all participants see the text, see how they have been represented and how others have been represented so that they had the chance to alter it.

In addition I have used alternative names for individuals and places so that I minimise the risk of people being identified. The meaning of the account is, arguably, far more important than the precise detail. By eliminating detail I have safeguarded against compromising the integrity of my work. However, many would disagree, Bochner (1994), Ellis (1994), Ellis and Bochner (2000, 2006),

Vickers (2010) with my approach and feel that a true autoethnographical researcher should be bold enough to stand up and say, 'this is my experience, I present it as a true story.'

Autoethnographers must stay aware of how these protective devices can influence the integrity of their research as well as how their work is interpreted and understood (Ellis, et al, 2001: 3).

Richardson (2001) does not use composite characters. In her work she suggests that by using a fictional character you lose the truth and the true place in the text and the relationship you have with that character. I agree in part that you are creating an imaginary world in which to place the experience, but I have done so for a very valid reason: not to cause potential harm to others. A research project that occurred in Springdale, New York was famously identified by the readers, as was the identity of certain individuals (Vidich and Bensman, 1958). For the purpose of my research I have given a pseudonym to the people and places that I have researched (Homan 1991:142-8).

Consequences

I discussed the consequences of my research with all storytellers. They knew it was intended to help influence inclusion for others by gaining knowledge rather than seeing it as an improvement of professional practice and politics (Hammersley, 1994). My aim was to produce true accounts for those lives that are being lived. By using an autoethnographical approach it rejects the notion that human experiences can be consistent, logical and be acquired by scientific, quantitative techniques. As Stake (2004) states that a qualitative approach leads to better gains,

Over the years I have realised that personal experiences often lead to a better understanding of meant and worth rather than measuring gains or comparing (2004:5).

When the stories were written I then had to consider how I was going to analyse them whilst keeping the integrity of the stories and the autoethnographical approach.

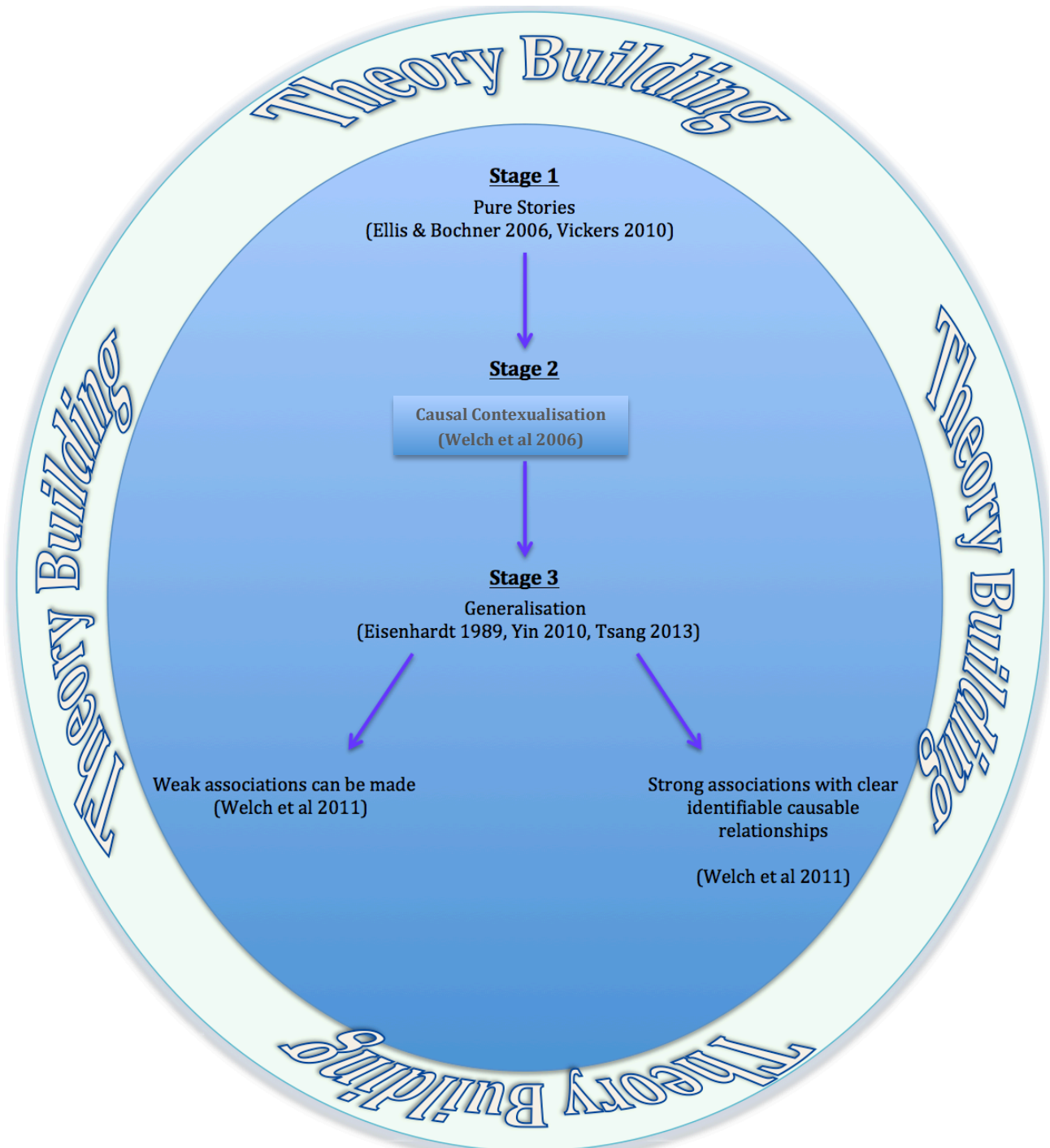
Using an analytical autoethnographical approach to generating theory.

I created my own analytical approach to generating theory.

To help you understand how I created my own model of theorising to help make sense of the stories I drew on the work from Yin (1984), Eisenhardt (1989a), Yin (2010), Welch *et al* (2011) and Tangs (2013) as well as previously mentioned Anderson's work (2006) Ellis and Bochner (2006).

I knew that I wanted to capture aspects of the purist approach to autoethnography where stories were seen as stand-alone pieces of gold: individual, unique case studies giving rise to questions and emotions in their own right (Ellis & Bochner, 2006, Vickers, 2010). Yet, I also wanted the rigour of an analytical approach to help me make sense of what was unfolding, (Andersons, 2006).

Fig 1. Shows my theorising model for my stories.



Firstly - A chapter dedicated to just the stories without interruption.

I wanted the story to be pure, uninterrupted and free flowing for all the reasons previously mentioned and endorsed by Ellis and Bochner, (2006).

This important stage allows the reader to do their own analytical work themselves. It allows the reader to search for his or her own meaning and identify issues that lie in and around the story by using their own structure of analysis. Stories can be seen as a form of cerebral voyeurism and can help the reader to transport the research into situations they understand through their

own lens. I hope that by using this approach I will invoke an emotional experience, which helps the reader to better connect with the storytellers by arousing a deep and powerful emotional response, (Rowland *et al*, 1990, Rolfe, 2002, Clarke *et al*, 2005, Furman, 2006, cited in Vickers, 2010). An unedited narrative, with flowing words, a story where multiple meanings can unfold for the reader without being channelled. I wanted to respect and value their stories by not touching them when first presented - raw and unruly (Ellis and Bochner, 2006):

Stories should be judged by aesthetic standards, by the emotive force by their verisimilitude and by criteria of authenticity or integrity to the people they portray (Badley, 2003:442).

I am aware that the stories told are only true from the individual storyteller's perspective. The quest for 'reality' and 'truths' is complicated, as each person will truly believe that their own story is real. This leads to this method of presentation being criticised for being too subjective, 'unscientific, entirely personal and full of bias' (Denzin & Lincoln, 1994: 4). However, it could be argued that all other research methods that pride themselves on objectivity for the 'facts' and 'truths' have in fact got subjectivity at the heart of their research. This could be because the researcher who reports it is intrinsically wedded to their own paradigm and own vocabularies. Any research already includes choices that a researcher has selected which by default make it subjective. As a researcher decides who, what, when, where and how to research (Tullis *et al* 2009), it begs the question, 'can a piece of research ever be objective?' (Rorty, 1982 Kuhn, 1996). I would question if you can separate the research from the researcher (De Certeau, 1984). There is a relationship between author and text. I do not honestly think that you can pretend that research is value free, (Bochner, 1994). The question also arises as to why do we want to seek truths? Personally, I am content with what people are sharing with me. I have no desire to prove it factual correct. For me, the story and the impact it has had on that individual and their family through their eyes is enough:

We shall not in the end arrive at an account of truth in fiction which will meet the orthodox criteria of a social science. Such an account would be

absurd (Clough 2002:88).

I am explicitly stating that my research is value-centred. My desire was for the reader to experience the lives and the attitudes of the storytellers. I wanted the reader to step into the storytellers' shoes (Talese and Lounsberry, 1996).

If I had not used this approach, I believe it would have limited my research as it would not have given the subjectivity this research needed to promote understanding and connections with others (Ellis and Bochner, 2000). Taking the stories in their purest form accommodates subjectivity. It allows the wider lens on which to view and to make sense of the world and how it really feels to the human encountering it (Wood, 2009):

Stories are complex, constitutive meaningful phenomena that teach morals and ethics, they introduce unique ways of thinking and feeling and helps people to make sense of themselves and others (Adams, 2008: 43).

For me, the beauty of storytelling through an autoethnological approach allows complex and quite delicate information and knowledge to become accessible to the reader (Hinde, 2001, cited in Parritz and Troy, 2010). It helps us to make better sense of the world in which we live (Gabriel, 1998). In essence it makes it real - 'story telling is an exciting and gripping way to reveal data' (Perl *et al*, 2007:306). I am always mindful, as I have said previously, that stories can embellish and reveal information that is only relevant to the person telling it! On one occasion my supervisor wrote; 'do you need to write about having triplets and the struggle you had getting pregnant?' Whilst it might appear irrelevant to the reader it is very much part of my story. Just the word triplets can conjure thoughts such as, 'hard work, prematurity, hospital' In addition it helps situate my experience and gives a privileged insight into my life. However, there are many who cannot see the relevance to social science. Maréchal, (2010) points out that the emotional and evocative genre of autoethnography discredits storytelling as the accounts could contain a 'lack of relevance as a result of being too personal' and for

for being biased, navel-gazing, self-absorbed, or emotionally incontinent, and for hijacking traditional ethnographic purposes and scholarly contributions (Maréchal, 2010,:45).

I would argue and state that in fact this approach is an important vehicle which can be used to obtain a real portrayal of what is happening in individuals' lives today (Holman Jones, 2005). I want the reader to have views before I let them into my thoughts and feelings so both of us construct knowledge and understanding through this process together. This way the reader is a co-researcher and co-knowledge constructor. 'Knowledge construction' as an epistemological position is important for both reader and researcher. Brinkman (2007) described this by using a traveller metaphor; where it is considered the researcher and the reader, the travellers, to be on a journey, wandering through the landscape, along with other inhabitants, asking questions. The meanings unfold and are constructed through the traveller's interpretations. This way I am not fixing theories; I am allowing for fluidity and freedom of thought (Ellis and Bochner, 2006).

By allowing stories to flow has been criticised for not helping point the reader in the direction of travel. Debatably, it should be interrupted because then this allows the reader to be led in unexpected direction to give the opportunity to bring into play our own faculty to establish connections:

It is only through inevitable omissions that the story will gain dynamism. Thus whenever the flow is interrupted and we are led off in in unexpected direction, the opportunity is given to us to bring into play our own faculty to establish connections for fulfilling the gaps (Iser 2000:104).

I agree in part and that is why the following stages of my analytic autoethnographical approach promoted a clear framework in which to analyse the stories. Again, I will reiterate I felt it important for the reader to have their time to read, digest and develop their own thought process before I revealed mine.

Secondly, I used causal contextualization explanation, Welch *et al* (2011) to make sense of each unique story (please see appendix 4). I used this typology to make sense of the theories that had arisen from each, unique story: their causes and their context. By using this approach I believe I have gone beyond the isolated individual and captured the social, political, cultural and institutional context in which human actions are related and occur, as Merleau-Ponty 1962, reminded us; man is but a network of relations. By using this approach knowledge is then constructed and firmly situated within a context. This notion of context can be best described by the hermeneutic philosophy which actively encourages one to analyse the story and to look beyond the here and now. It encourages us to look at the contextual interpretive perspective provided. Gadamer (1975) prompts us to remember that every text derives its meaning from a context. By taking this approach to analysing the stories told it allowed me to value each individual, unique story and start to develop a thorough and comprehensive understanding of inclusion as it is played out right now. However, sometimes context is lost when the researcher starts to find common ground between each unique story:

We consider how the case study generates causal explanations and how it incorporates context—two features of the case study that are often regarded as being incompatible (Welch *et al* 2011:740).

This notion of incompatibility needs to be explored. Tsang's, (2013) argues that incompatible does not exist, as there is always a relationship between causal explanation and context. This is true if you just analyse each story as a separate research project as each story is highly contextualized: it is this that helps makes causal explanation of events that have occurred. However, if you then start going across each unique story and try to make sense of a series of multiple case studies causal and contextualisation then start becoming incompatible as you lose the highly personalised context in favour of explanations.

This lead to my third step of generalization

I felt Welch *et al* (2011) work on causal contextualisation did not allow for making generalisations, (Tsang, 2013). However, I considered it an important step to do before I could generalise. Firstly, I wanted to examine each case in detail: then I wanted to draw rich, interconnected information from each singular case study to get insights across the stories told, spotting similarities and differences between the case studies (Yin, 2003), (please see appendix 5).

But by generalising I moved away from the highly personalised contextualisation that each unique story presented. In addition I further moved away from the purist approach to autoethnography (Ellis and Bochner, 2006), 'Since to theorise is to generalise away from context' (Welch *et al* 2011:743). To generalise involves de-contextualisation. Whilst this was a concern I deliberately did this to allow more meaning to unfold. I had already explored each unique story, and given the reader a chance to read them raw- a true purist approach (Ellis and Bochner, 2006; Vickers, 2010). But this next stage was important to discover commonalities, as it was clear that there were many. This is why I found Anderson's analytical approach helpful in developing my autoethnography methodology (2006). This has already been discussed. I did not want to shy away from generalisations and taking an analytical approach for fear of diluting a purist take on autoethnography- far from it; I wanted to stand proud and say that you can have both in the same piece of work, enhancing the experience for all; a dualism approach to autoethnography.

By using generalisations across the multiple cases it allowed me to analyse similarities and differences between each case. Yin, (2003) described how multiple case studies could be used to either 'predict similar results (a literal replication) or predict contrasting results but for predictable reasons' (theoretical replication) (Yin, 2003: 47).

In addition, I wanted to accomplish something other than just understanding a particularly unique situation, so I took this approach (Stake, 1995) to allow each narrative to be scrutinised in depth. According to the definition held by Stake

(1995) my stories were instrumental in accomplishing something other than just trying to understand each unique story. This approach gave me the ability to gain insight and understanding of a particular situation across the multiple narratives without it being too narrow and with limited transferability of interest (Stake, 1995).

I wanted to explore rather than just explain (Welch *et al*, 2011). I used two theorising components from Welch's *et al* work (2011)- inductive theory building and natural experiment to build my generalisations. This allowed me to make weak associations and stronger associations. Welch's *et al* work (2011) highlights inductive theory building as identifying common associations but not having underpinning relationships between the causes of these associations; so weaker associations. In addition I wanted to spot stronger associations. This is where Welch *et al* highlights the need for recognising the relationships that causes the associations. Tsang (2013) strongly disagrees with the use of the weaker association methodology:

It is inconceivable that researchers would present their case findings just as associations between events without specifying the underlying causal relationships (Tsang, 2013:324).

In addition the danger of generalisations across multiple stories can lead to restraining our curiosities and interests as one tries to make links (Stake,1995). Also, sometimes the links identified are simply not there or sometimes multiple case studies can be accused of making unjustifiable generalisations. I used Welch *et al's* , 2011, approach, as I wanted to go deeper. It allowed me to identify subtle and more obvious generalisations across the stories. I wanted to get as much as I could from the stories told.

Conclusion.

My epistemological aim was to retell the stories in a meaningful, truthful way and to retain the stories' authenticity. I wanted to uncover social meaning or practice in order to gain more knowledge and use an autoethnological approach

as it had more of a literacy focus, which was accessible. My hope was that by using this approach I have promoted a deep connection with the subject. I craved to get to the heart of the matter and explore the real human impact of inclusion, Moro, (2006). Using aspects of the purist approach to autoethnography, where stories were seen as stand-alone pieces of gold: individual, unique case studies giving rise to questions and emotions in their own right (Ellis & Bochner, 2006; Vickers, 2010) combined with the rigour of an analytical approach has helped me make sense of what unfolded, (Andersons, 2006). This methodology has allowed me to achieve this. The stories told in chapter 4 and my findings in chapter 5 are testimony to this.

My next chapter contextualises inclusion and special educational needs by looking at the historical and current conversations that have surrounded these concepts. This was important to allow me to better understand the stories told.

Chapter 3

Contextualising Special Education Needs and Inclusion

How has the current inclusion and SEN culture grown?

A historical overview and current position.

My aim in this section was to analyse the present and historical political conversations, which have taken place around the concept of inclusive education and Special Educational Needs, SEN. I have examined how inclusion has arrived at its current position. Tracing the antecedents (conditions, context and background information) has allowed me to gain a thorough understanding of what is being said today for those with SEN within a mainstream schooling setting, Stake (2004). What was very evident from this analysis was that SEN holds different meanings for different people. This contextualising chapter has helped me to make sense of the findings from my research.

Firstly, I had to understand what the term Special Educational Needs (SEN) means?

Roughly, one in five pupils have been identified as having SEN as Statistics published by the government in 2014, showed that 17.9% of the mainstream school population has special needs, which equates to 1,492,950 pupils (DFE, 2014). This can either be seen as a decline since 2010 where 21.1% of pupils had SEN, (DFE, 2014) or a response to a call for less children and young people to be identified as having SEN, (Marks, 2000) and Conservative Party Review of SEN, (Conservative Party, 2007).

A child has SEN if he or she has a learning difficulty or disability, which calls for a special educational provision to be made for him or her. For the purposes of the SEN provision, it includes any child or young person up to the age of 25 who is registered at an educational establishment. Today, SEN as a legal definition refers to children who have learning difficulties or disabilities that make it more difficult for them to learn or access education than the majority of children of the same age (Education Act, 1996, DfEE, 1996 and SENDA, 2001b DfES, 2001b, section 312, Children and Families Act, 2014).

However, the concept of 'SEN' is worth wrestling with. As whilst the term appears familiar in practice it proves to be rather complex due to the differing values and priorities that are attached to it. It has different meanings for different people, in the different contexts in which it is being talked about (Terzi, 2005).

The term special needs was introduced in 1970 in United Kingdom and can be attributed to Professor Ron Gulliford, the first Professor of Special Education in the UK, (Wedell, 2005) and was adopted by the Warnock Committee, (DES, 1978). The committee wanted to replace the previous definitions of handicapping impairment categories that were being used in schools following the Education Act 1944:

The handicapped impairment categories were as follows:

- Blind
- Partially sighted
- Deaf
- Delicate
- Diabetic
- Educationally subnormal
- Epileptic
- Maladjusted
- Physically handicapped
- Speech defect

(DoE Education Act, 1944:5)

The aim was to move away from perceived deficit categories- from what students could not do, to what was required educationally to help them progress.

We wish to develop a more positive approach and we have adapted the concept of special educational needs, seen not in terms of a particular disability which a child may be judged to have, but in relation to everything about him, his abilities, indeed all the factors which have a bearing on his educational progress (DES, 1978: section 3.6).

Paradoxically, over 35 years later the current UK government still uses terms with perceived negative, deficient connotations such as 'difficulty', 'impairment', 'need', disorder and 'disability', (Children and Families Act, 2014). Today, arguably, it is even harder to define, as confusion exists between people's understanding between 'special needs' and 'special educational needs'. (Frederickson and Cline, 2002) A special need might be identified in the Equality Act, (2010), but not be seen as a special educational need and this could be true the other way around. Furthermore, to add to the complexity, the Ofsted review (2010) into SEN, found that the language of special educational needs had become confusing across multi-agencies. Health services refer to 'disabled children'; social care services to 'children in need', and education to 'special educational needs'. The review clearly showed that that there was an inconsistency as to how the term was used and enacted. SEN appears to be an ambiguous term. My research findings clearly echo this.

In the schools where the research took place SEN was defined by the following categories. This was in line with the New Code of Practice, (2014):

A) Cognition and learning needs

- Specific learning difficulties (SPLD) including dyslexia, dyscalculia and dyspraxia
- Moderate learning difficulties (MLD)
- Severe learning difficulties (SLD)
- Profound and multiple learning difficulties (PMLD)

B) Social, emotional and mental health difficulties

- Behavioural needs

- Social and emotional difficulties; which include attention deficit disorder, attention deficit hyperactive disorder or attachment disorder and including behaviours that may reflect an underlying mental health issue such as depression, self-harm, substance misuse and eating disorders.

C) Communication and interactive needs

- Speech, language and communication needs (SLCN)
- Autistic spectrum disorder (ASD) including Asperger's Syndrome and Autism.

D) Sensory and or physical needs

- Visual impairment VI
- Hearing impairment HI
- Multi-sensory impairment MS
- Physical disabilities PD (Code Of Practice, 2014: 18).

It would appear ironic that today we use the above categories to define SEN when Warnock in 1978 and the Education Act, 1981, attempted to reduce categorisation of disabilities by reducing the difference between 'handicapped' and 'non-handicapped' students with the removal of categories that had existed since the 1944 Education Act. Warnock wanted to eliminate categories because

Categorisation perpetuates a sharp distinction between two groups of children the handicapped and non-handicapped and it is this distinction which we are determined as far as possible to eliminate (DES,1978: section 3.2).

However, Warnock's work was also mindful that there was a need for categorisation to ensure professionals and local authorities knew the children's and young person's needs and therefore had an obligation to respond accordingly and make sure that those needs were met. This discussion of whether or not to categorise need is still on-going today as it can be seen as, 'a safeguarding tool for the rights of the child to an education suited to his needs' (DES, 1978: section 3.30).

Debatably, categories are necessary in order for the professionals such as the speech and language therapist, hearing support advisory teacher, physical impairment advisory teacher and others be able to provide a formal assessment and to write a detailed report that would contribute to an individual's Education, Care and Health Plan (ECHP). This in turn gives information to fellow professionals and parents as to what the educational need is. Without categorising or recognising the specificity of the education need, how can you put strategies in place to help? The content of professional reports, questionably, still focuses on what they cannot do rather than what they can (Goacher *et al*, 1988). So, they could be perceived as using a deficit model.

It is quite evident that we have not replaced the categories at all. Maybe we have just softened the words so they are less offensive in today's understanding, e.g. replacing 'educationally subnormal' with 'mild to moderate learning difficulties' so, perhaps reducing the negative connotations that were attached to the 1944 definitions. SEN can, therefore, be seen as an overarching term that encompasses the many different categories like the 'super-category' (Norwich, 2013). The focus on individual needs is meant to be at the heart but, however, the current SEN categories are surrounded in criticism for using labels that devalue and that are discriminatory (Solity, 1991) and expresses a language of prejudice (Corbett, 1996). Words such as 'difficulty', 'need', 'disorder', 'impairment' conjure up deficient character traits. We appear to have not softened our terminology at all instead replaced a list of historically acceptable terms for another. The current language of SEN does not abandon the deficit language that Warnock in 1978 was so desperately trying to reduce. It could be claimed that the non-labelling strategy was just phony, (Soder, 1989). What is apparent is that SEN is still poorly defined and can be vague and lead to postcode lottery and different definitions and interpretations depending on who is defining it (Norwich, 2103); this variance is unacceptable. Runswick, Cole and Hodge (2009) consider the SEN term excludes pupil's psychological and social wellbeing and it cannot possibly be seen as neutral or benign. They see this term as being unhelpful. Parents could see a SEN label as possibly distressing, (Dumit,

2006), where they view it as unsupportive and a narrow definition of their child. Other negatives could result from a having a SEN label:

stigma, bullying, reduce life opportunities, reduce expectation focus on deficiencies, missed classification, uncertainty about definition of subcategories, labels are not necessarily lead into specific interventions (Norwich 2013: 43).

However, some parents might feel that it is an incredibly helpful tool to have a label for their child as highlighted in the work of Brogan and Knussen, (2003). This can help them to explain and understand why the child is behaving in such a way and can help explain why their child is underperforming, (Farrugia, 2009 and Rutter, 2011). It can help achieve the right support, provision and strategic approaches to learning. Interestingly, other studies show that parents and students jump between finding a label helpful one minute to finding it a hindrance another. Skelton and Valentine's, (2003) research illustrated how 20 deaf students interchanged between deafness as a 'disability' and deafness as an 'identity' depending on when they needed to use the labels. This is echoed in my household with my own son: one minute claiming he cannot do something because of his deafness, to other times being proud and promoting his deaf identity. In a more recent study, Russell and Norwich, 2012, examined 17 parents' responses to their children being labelled with an Autistic Spectrum Disorder, ASD. Dilemmas existed for parents as to whether to retain the 'normal' status of the child or to use the label. It would appear that the labels were used and valued at different times depending on what they needed to gain from using them.

Laughlin and Boyle, (2007), came up with 5 reasons how labels might be used well:

- 1) Labels open door to resources and interventions
- 2) Labels are awareness raising and promote understanding of particular difficulties
- 3) Labels reduce ambiguity and provide a basis for clear communication
- 4) Labels provide comfort to children and families by explaining the difficulties

- 5) Labels provide people with the social identity and a sense of belonging to a group.

(Laughlin and Boyle, 2007:28)

The bottom line is that a SEN label can be both positive and negative and is different to different people at different times. The value of them metamorphoses in differing situations, as does the currency they hold. Also, it is worth questioning who defines what is normal cognitive development, normal body and behaviour? Is there a norm? As by saying one type of cognitive learning profile is desired or a certain physical body type, we attach value to it and assume a certain set of learning skills and physical attributes that people aspire to have. Having a standard of 'ableness' which others are measured against.

It's a burden to us to be human beings- men with our own real body and blood; we are ashamed of it, we think it a disgrace and try to contrive to be some sort of impossible generalised man.

(Fyodor Mikhailovich Dostoevsky (1821- 81) Russian Writer, cited in Scanlan, 2002:p24)

Arguably, if we did not value certain cognitive skills or certain physical qualities would there be a need to identify students as 'special' in schools? (Hargreaves, 1983) As it could be seen that many disabled people or people with difficulties retain an ineradicable conviction that they are fully human (Hunt, 1966). This would further suggest the concept of 'special educational need' remains within a deficit base; in other words you have a default that is not normal and you are in some way sub-human. This will be further explored in the subsequent sections.

Each child in my research have been identified as having SEN:

- Nick, has a Hearing Impairment
- John, has autism
- Archie, has Attention Deficit Hyperactivity Disorder (ADHD) and Asperger Syndrome

- Frankie, has autism and diabetes
- Ian has been diagnosed with autism.

Even though these children in the stories have been identified as having special educational needs and have been put into seemingly appropriate categories, it is clear that SEN definitions can be open to interpretation by the person who is responsible for defining it. Who defines the needs and who has the power to say what category someone falls into? At present it is usually the school or medical professional rather than the parents or students themselves. The students respective Special Educational Needs Co-ordinators (SENCo) have placed each of the children in the stories into categories based on the information that was available to them. Although, in section 7:52 of the Special Needs Code of Practice (CoP) DFES, (2001a), there is advice and guidance on how to identify those with SEN it would appear that in practice it is problematic as it is too subjective. This still has not been solved by the introduction of the new Code of Practice, 2014, as the advice is too general and open to interpretation. In addition two people who have been put into the same category have clearly different, unique needs: no two people are the same.

However, despite the complexity surrounding the term SEN I intend to continue to use it throughout this thesis as it is the language of the current education system.

Once a student is identified as having SEN the question of inclusion is then brought into the foreground.

I will now attempt to define inclusion and its multi-dimensional meanings. I will examine inclusion through a social justice perspective; the views of students; the involvement of parents and the rise of assessment and accountability. I will look at the different values and interpretations that are attached to these meanings and how they have shaped the current inclusion discourse and what this means to a child in a mainstream environment. The last section in this chapter will analyse the current position.

Multi-dimensional inclusion: a social justice perspective.

Many aspects of historical, national and international perspectives have led to inclusion being viewed through a social justice lens. This, in addition to the Equality and Disability legislation, has been fundamental in shaping inclusion for those with SEN.

As long ago as 1792, Thomas Paine wrote the 'Rights of Man'. His paper discussed how some groups are excluded and not valued and how other groups seem to hold the power and authority. Arguably, his paper has shaped and influenced inclusion over the centuries. Even in the 1700s he talks of the need to have laws, which offer a guarantee against discrimination and highlights the absolute need to offer opportunities that are not restricted by irrelevance. The rights of the man, Paine argues, are the only things that are truly hereditary. You are born with rights.

Men are born and always continue, free and equal in respect of their rights. Civil distinctions therefore, can be founded only on public utility (Paine, 1792: section 12).

It highlights that all men are born equal and it is the society in which they live which causes distinctions. Interestingly, 300 years later we are still wrestling with these concepts. Laws, however, are now firmly in place. The Disability Discrimination Act 1995, 2005, Human Rights Act 1998, and the subsequent Equality Act 2010, have played a momentous role in shaping the current inclusion discourse through a social justice lens by giving it legal weighting and raising the profile of special education needs and disabilities within our society. The Acts have human dignity, and equality of opportunity firmly at their roots. This gives more weight and security for the rights for the child.

A Rights' based strategy has been influential but it is a spurious discourse. Human rights are arguably the single most important political development for recognising disability and need (Bickenbach, 2001):

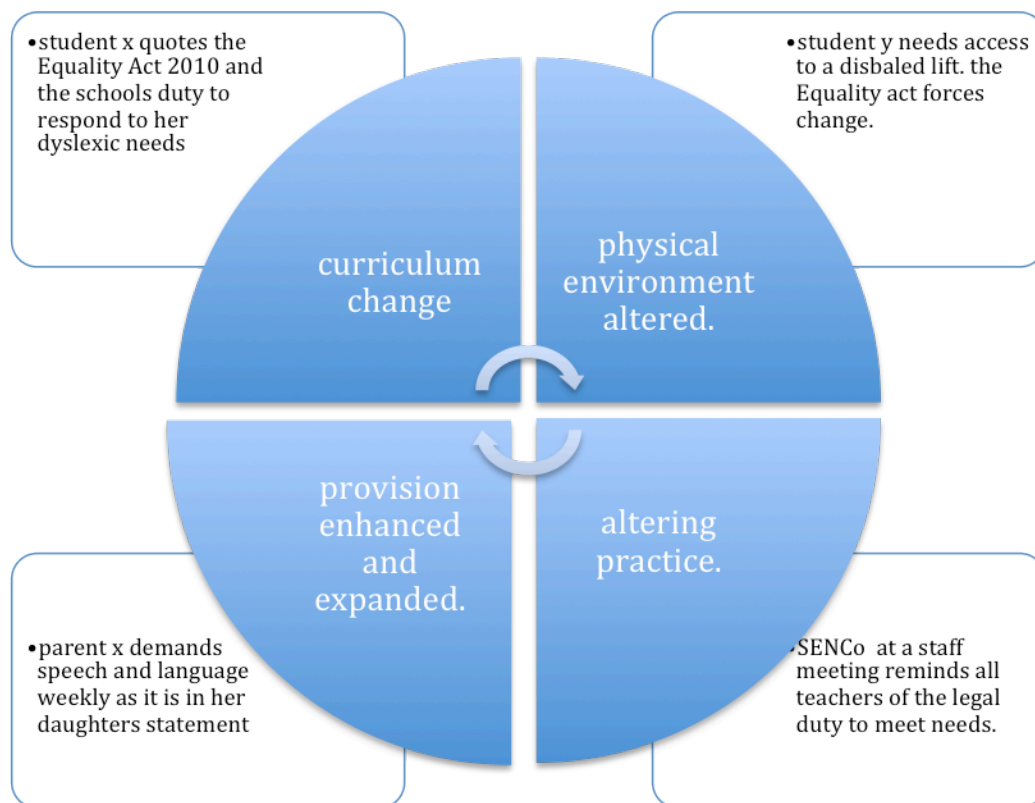
The commitment to rights by the membership has led to significant social change as national assemblies consult and work with the government to implement rights based approach to disability (Hurst, 2003:168).

However, the weakness of human rights are that they are never commensurable -my right may be different and conflict with your rights (Fish, 1994). When it comes to human rights it is difficult to say what they are unless you make reference to a set of common human rights or interests (Fagan, 2005). Who decides what the common human needs and interests are? This is fraught with problems (Doyal and Gough, 1991). The so-called objective interpretation of human needs could be responsible for social disillusion and scepticism. However, there are different views that exist about having a set of common human rights goals that we aspire to have. A neo-liberal viewpoint could view a common set of needs and rights as being too authoritarian and could be seen as a metaphysical fantasy (Gray, 1983) others may see having a set of general rights as potentially open to social and historical relativity, and open to cultural domination, whilst other views may see human rights as basic need, for example, water, food, shelter. Maybe it is just safer and morally correct to ask the individual with SEN what they think their human rights and needs are. This is very much the focus of the new Children and Families Act, 2014, where the children and young people appear to be at the heart of decision-making and their voice sought and valued. However, it is too early to measure the impact of this new law. The danger that could arise is that those in more powerful positions could feel that they know best: ignoring personal preferences and in turn shaping the inclusion discourse. You can see this being played out in many school staff rooms across the country. I have heard countless times in staffrooms... 'what they need is...'

The human rights agenda has been promoted by recent legislation, in particular the Equality Act 2010, which actively promotes equality of opportunity. If you see equality of opportunity as a human right with legal backing then it could potentially shift the focus, the mind and the curriculum and there would be no need to plea for what is your right. As Bandman points out that rights should

allow one to stand with dignity and if necessary demand what is: 'our due without having to grovel, plead or beg' (1973:236).

The following is my interpretation of how legal weighting could affect change.



This could then encourage an objective distribution of resources and could avoid localism where differences in provision and responses occur.

The emergence of the rights of children, young people are important for empowerment and the development of structure and inclusive practice. It can shift and encourage changes in values and mentalities.

To what degree equal opportunities can affect the right sort of change needs to be challenged. Questionably, the equal opportunity industry is dependent on the continuance of inequalities. It seems to be the more confusion surrounding equal opportunities the better as it serves to demonstrate that not only is it a

complex policy area but it allows for foul play to occur; all under the guise of doing it for inequalities and social justice (Cockburn, 2001).

The complexity is merely a diversion serving to draw a veil over the eyes of the public in order to disguise the true role of equal opportunity policies (Edelman, 2001: 68).

The purse of the state, if we take a pure economic approach to our capitalist society, (this will be looked at in more detail later) drives social justification for allocation of resources. Equal opportunities could be seen as a convenient way to control the economy, a clever mechanism by which governments can make unpopular decisions under the guise of doing it in the name of inequality and social justice (Bank, 2007) for example Disability Living Allowance is in the process of being replaced with Personal Independent Payments. This has been highly criticised (Scope, 2014) due to the assessment criteria being flawed, the concern is that undue hardship will occur for many disabled people as the focus seems to be on cutting the welfare budget rather than focusing on what disabled people need. In addition many services are being outsourced in the name of market capitalism, consumer sovereignty, self-reliance and economic and political freedom, (Edelman, 2001):

Market mechanisms are displacing the state services and they are being outsourced to hybrid public-private organisations and there is an increasing devolution of responsibility for self-management, choice making, and the management of risk away from state institutions (Ozga, 2011:307).

This is very evident in the setting where the research took place. The schools are academies and have more autonomy over curriculum, spending and services. Yet less is given to each school year on year. It would appear that the economy sets the agenda for the education and equality opportunities policies. However, the agendas can be seen like shifting sand and changeable. Edelman's, 2001, work highlights the misidentification of what society focuses on to improve equal opportunities.

An important reason the problems for the disadvantaged are allowed to

remain and fester indefinitely is due to the misidentification of the issues to be addressed (Edelman, 2001:68).

The misidentification of focus further confirms how the economy led approach sets the agenda. We will only get to grips with equal opportunities and social justice when economic indicators and the maintenance of the free market do not determine government policy. Social justice is a contested term but features prominently in the national education policy rhetoric e.g. 'Equality for All' (UNESCO 2004: I). It appears still to be a top priority.

Equal opportunities is not a coherent notion, it is highly contestable.

There are a number of analytical frames that can be laid over the equal opportunities' phenomenon to help make sense of it, especially as I see the problems associated with it going beyond the effects of the economy (Bank, 2007). With the rise of capitalism the hegemony of able-bodied normality has become the benchmark for judging others with impairments, 'less than human' (Oliver, 1995: 89). Cultural imperialism is further developed due to a national preoccupation with charities, (Barnes, Mercer and Shakespeare, 2003) portraying those with disabilities in need of something. This perpetuates an image of helplessness, despair and dependency. This is further embellished by media representation of those with SEN, such as TV titles like the 'Undateables' (Channel 4, 2014-2015). So the need to see capital beyond monetary and in terms of the physical body and how one fits socially is imperative.

Bourdieu's work (1977, 1983) is particularly helpful. He offers a set of thinking tools known as *structure* and *agency*. This is how the individual, the *agent*, relates to society, the *structure*, and their relationship and who exercises power over what. He talks about this in terms of *capital*, *habitus* and *field*.

In its simplicity, capital is something that can be transformed into something else e.g. land into money, knowledge into power, power into status. What is useful about Bourdieu's work is that he goes beyond the narrow definition of capital being just about money (Bank, 2007). This is important to understand

equality of opportunities and the impact it has on individuals with SEN and inclusion.

He suggests that there are three main forms of capital:

- **Cultural** (attitudes and dispositions)
- **Social** (networks and relationships)
- **Economic** (financial, land or property)

(Bourdieu, 1983:82).

Further analysis of capital also encompasses:

- **Linguistic** (use of understanding of language)
- **Political** (power and influence over decision-making) 6) **Symbolic** (knowledge/qualifications)
- **Physical** (dress, body, body shape, body features.)

This has an impact on equality of opportunities because the capital is unequally distributed in quality and quantity both in the community and for individuals, (Thomas and Loxley, 2007). So, if you look at the seven categories and overlay a student profile with profound and complex needs and disabilities you would soon come to the conclusion that they would have less 'capital' than others, and less to 'trade' with. By participating in this 'capital game' we are reinforcing domination and subordination. So it would appear that the SEN children with any sort of difficulties or disabilities are at a distinct disadvantage and are not having access to equal opportunities or able to operate as a disabled entrepreneur.

Some forms of capital have different values to different people at different times. In addition different capitals attract different values within the marketplace depending on when you want to exchange them. People and individuals and communities compete for capital. Potentially, the more capital you have, the stronger your position in society and you will have a stronger sense of 'self', especially if you add Reay's suggestion of **emotional** capital to the list, (Reay, 2004)

Capital can be exchanged, converted, reconverted to produce power and domination (Harker et al, 1990: 23).

The cultural capital is central in education (Bourdieu, 1983). It is a dominant feature within the school environment. The cultural attitudes and values that embody a school are, arguably, universally recognised, 'being good', 'doing well', 'being well behaved' 'having a degree of intellectual ability', and 'sharing the same positive attitude towards the schools values and systems' (Thomas and Loxley, 2007: 148). If you do not adhere or share these cultural understandings then you could be seen as a 'deviant' or a 'nuisance' or someone who just 'does not fit'. For instance sometimes a child with autism may find the noise of other children, especially at break time within a secondary setting, too much and may just stand in a communal area, frozen to the spot, rocking violently backwards and forwards screaming; this behaviour could be perceived as unacceptable and not what a school wants culturally. In addition it further reduces that particular students' social capital amongst his peer group as s/he is seen as 'odd'. This reinforces inequalities and weakens the capital currency for those with SEN and shapes the inclusion discourse, (Lamont and Lareau, 1998).

Bordieu's model of capital and its exchange needs to be redefined to clearly show the negative effects on a child/ young person with SEN and the impact it has on inclusion. This will be looked at in more detail in my findings' section.

Bourdieu's work (1983) also talks about *habitus*; how the individual agent reacts within the structures of society. Habitus can be viewed as who we are physically and psychologically and how the fields in which we have lived and passed through have shaped us. The families that we are born into, the structures that surround our families, the roles within our families, the values, the norms as well as the community in which we live all affect our habitus. Our habitus makes us behave in a certain way and in turn reproduces habitus.

The management of self is critical - how we display ourselves; our habitus - our deportment, our style, our body movement, what we say, how we say it all affects the capital we have. If we are born with physical impairments or

disabilities this affects everything about us. My son, born profoundly deaf, speaks with a deaf intonation- both his deafness and his speech is central to his habitus and affects his emotional, physical and social capital. We attach huge value to the body. 'There are substantial inequalities in a symbolic values according to particular body forms' (Shilling 2004:477).

Bourdieu also talks about field; these are what he considered to be external forces. The way one acts as an individual is determined by larger forces at work, something we have very little control over. All of these channel our 'being' and how our habitus responds. He talks in terms of :

- 1) **Institutionalised fields**, such as schools, politics, economy,
 - 2) **Hierarchical roles** e.g. teacher, headteacher
 - 3) **Hierarchical structures** that create dominate and subordinate roles and posts.
 - 4) **Historical factors** that have affected how we are today and
 - 5) **Underpinned by values goals and norms** at a particular moment in time.
- (Thomas and Loxley, 2007:89).

All of these are fluid and changing over time. What I would like to propose is that the interpretation of **field is further developed** to consider the psychological make-up of a student with certain recognised disabilities such as autism in addition to just seeing *field* influenced by external forces. As I believe their neurological pathways and make- up of the brain creates an internal field that every part of their 'being' / 'habitus' has to pass through. This is out of the child's control, yet controls everything.

What is clear is that anyone with any form of impairment or disability is at a distinct disadvantage in a capitalist society. A need to go back to basics is called for. Making someone feel valued and respected has to be our starting point. Listening to our students, giving them a voice and making them feel a sense of belonging should be our uppermost priority.

That everyone feels included in everything that you do and respect the tenants of utilitarianism...where contentment and happiness and respect for all should be our starting point for human rights and equality of opportunity for all (Kitayama and Marcus, 2000:45).

Multi-dimensional inclusion- the views of students.

Giving young people a voice has been promoted through recent government documentation both at home and abroad. The UN Convention on the Rights of the Child (1989) Article 12 gives the child the right to express their views on matters that affect them. Subsequent government initiative such as Every Child Matters (DFES 2003a) and the 2020 Vision (DFES 2007b) have encouraged schools, colleges, local authorities and other services to seek the views of the child and young person. In its simplicity the concept of including the student's views is admirable however, to be able to have a voice you have to be able to express what matters to you and it needs to be valued and 'heard'. Even when there are effective systems in place to gain these views there are many tensions involved in accessing students' perspectives.

What is striking about recent government education literature related to those with disabilities is that they all appear to define inclusion within a neo-liberal framework; where the voice and empowerment of the student is critical and fundamental. Neo-liberal governmentality rationale can be viewed as encouraging individuals to be autonomous entrepreneurs of their own lives; life is regarded as an enterprise, qualified in terms of competencies, choice, investment, human capital and geared by highly diverse needs. If I develop this notion and see neo-liberalism through a Foucauldian framework, then it would suggest that neo-liberalism is to govern the economy as a domain of freedom and to reinforce society through this government (Foucault, 1987).

Underpinning the neo-liberalism rationale are choice, power, knowledge and partnership. This implies that students with disabilities would need to obtain certain skills in order to operate within it.

This needs to be further explored, as this has significant implications for those with learning disabilities and the inclusion discourse. It could possibly lead to ethical dilemmas surrounding the status and meaning of the body. The concern could be with the possible changing view of how we see the body to fit within a neo-liberal framework. The body could increasingly come to signify attitude, control and validity (Giddens, 1990) and have immense symbolic value. At a very fundamental level it implies that to be able to operate within this framework, you must have the necessary skills and mental capacity to be able to communicate and participate in a self-autonomous manner. This was clearly evident in Bourdieu's work on capital, habitus and field. This re-defines 'inclusion' as only those who can engage with the concept of 'personal entrepreneurship'. Inclusion is then owned by society and only by those members who can actively partake:

Inclusion as an idea in education probably rests at least in part on its consonance with the wider notion of inclusivity in society; for example a society in which each member has a stake (Thomas, 1997:104-5).

This could potentially rebound on the disabled student and shape disabled identities. What impact will the decisions made by the schools, colleges, local authorities and sencos have in promoting a neo-liberal view of inclusion? Rix *et al* (2010) work describes students with SEN suffering from 'persuasive paternalism' or 'observation by professional' where their ability to participate is doubted or even considered impossible, so the adult or parent is then considered best placed to make a decision on their behalf. Even the UN Convention wording is contentious; words such as **capable** and **maturity (12:1)** are used when a child expresses their views. This then leaves the reader to interpret their understanding of 'capability' and 'maturity'. As Morris states:

Our vision is of a society which recognises our rights and our values as equal citizens rather than merely treating us as a recipient of other people's good will (Morris 1991:10).

My apprehension is that the decisions made could have a potentially devastating effect on how the disabled body is perceived and valued and that inclusion will only be accessible by the students who have the necessary skills to participate. Their decisions could shape educators' epistemological position on their understanding of those with learning disabilities quite significantly. It could help to promote inclusion or serve as a tool to further drive a wedge between those with and without disabilities.

Children with special educational needs could be seen as a big object of concern rather than students in their own right, with their views represented rather than sought, known or understood: where parents' rights always trump children's rights (Osler, 2010). They could be seen as 'being done to': recipients of other people's decisions. OFSTED (2010) writes of the importance of discovering student views. Ofsted's findings showed that children and young people with SEN wanted successful relationships and friendships, independence: including the choice about who they lived with, choice about what to do in their spare time and the opportunity to work. This seems to be at odds and different to what their parents wanted. Parents prioritised happiness and safety for their son or daughter. This is concerning as it is usually the parents' perspective that is adhered to. If we focus on SEN students views then that would certainly help inclusion to become more centralised rather than marginalized, 'Nothing about us, without us' (Charlton, 1998:3).

A concern is that the schools and colleges are not able to give the students the necessary skills to fully participate in a neo-liberal inclusive model. This could mean that those with learning disabilities do not receive the freedom, which other able entrepreneurs can access. I propose that we are potentially creating an unintentional discourse, which hints that those with disabilities are 'less human' and have less right to freedom and an independent life. This reinforces Oliver's (1995) claims that those with disabilities are seen as less than human. Ethically this cannot be acceptable. Instead I believe that we should be seeking ways to enable students with disabilities to be able to fully participate by widening society's interpretation of what it means to be a disabled entrepreneur

within a neo-liberal inclusive landscape; again starting with the notion of value and respect.

The seeming lack of power the students have is a very prominent feature of the current education system; which is at odds with a neo-liberal inclusion model-where choice is a strong feature. Foucault's work on 'governmentality' is helpful in allowing me to better understand it. He illustrates the relationship between knowledge and power and the effect it can have in shaping individuals' subjectivity and in particular social activity. He concentrates on 'vision', 'knowledge' and 'doing' as the coordinates of power (Foucault, 1980b). It would appear that the current thinking surrounding inclusion leads to the government holding the power which is then imposed on others. This results in the social positioning and activities of the subjects e.g. in this case the students, providers, and the Local Authority. A Foucauldian perspective further recognises how power and knowledge influence language and symbolism. This in turn can influence a discourse and influence how we construct disabled identities and our perception of a disabled population. It will be interesting to see the landscape in several years' time when the current legislation has had time to be played out.

However, there are limitations to using Foucault's work on governmentality to help me understand the decisions made as he does not highlight the importance of 'self' in transforming the course of one's own life. Even though it can be recognised that some of our students lack the mental capacity to fight what is being imposed on them, there are others who are perfectly able to voice an opinion of wants and desires. Bill Hughes writes about the limitation of using Foucault's work as he feels Foucault puts the body as a 'docile target of power' (Hughes, 1999: 80). He claims that Foucault fails to recognise the importance of body as 'self' and 'social transformation'. This is echoed in Chris Shilling's work.

The bodies that appear in Foucault's work do not enjoy a prolonged visibility as corporeal entities. Bodies are produced but their own powers of production, where they have any, are limited to those invested in them by discourse. As such the body is dissolved as a casual phenomenon into the determining power of discourse and it becomes extremely difficult to

conceive of the body as a material component of social action (Shilling, 1993: 80).

If I used Hughes' interpretation of Foucault's work then I could view the disabled voice as a disembodied play of discourse. Reducing the human body to fiction, a body, which is devoid of material substance, a body that is distinctly absent from Foucault's concepts, I would argue, would have serious ethical issues.

The body is constituted as passive, without agency, the plaything of discourse and text, and a surface ripe for inscription (Hughes, 2008: 85).

I am sure that Foucault would claim that self-empowerment is a fiction and that the actions of those with disabilities are just a discursive product of power. A concern is that I think that Foucault is right. I believe it exactly describes the current inclusion discourse, which is played out under the guise of student voice and empowerment. The decisions that are made by schools, colleges, local authorities could be shaping their identities without them even being aware that it is happening. Even more tragic is that some of those who have been part of this research project display childlike trusting characteristics, especially of those in authority. They could have been unwittingly exploited as they are led to believe that they are being included at a local level in an all-inclusive society. The body cannot be just simply an epistemological construct-the body has to be able to influence and shape what is happening to them. It cannot be just a reflex to power but needs to be a practice of freedom.

We need to build an inclusive model, which really promotes the student's voice. In order to do this we need to widen society's understanding of what it means to be a disabled entrepreneur within a neo-liberal inclusive setting. Then and only then will our disabled peers be empowered and have the freedom that is only afforded by the able bodied. Everyone has the right to acquire skills which will enable them to gain suitable employment, suitable living arrangements and be a valued, contributing member of society.

Parents play an important part in the inclusion arena. To what extent they are involved and how they are involved can help shape the inclusion experience for children and young adults. This will now be looked at.

Multi-dimensional inclusion-the involvement of parents.

Since Warnock 's report in 1978, parental involvement has been high on the agenda and has influenced and shaped inclusion. The report advocated for parental involvement in decision-making:

The successful education of children with special educational needs is dependent on the full involvement of their parents; indeed, unless the parents are seen as equal partners in the educational process the purpose of our report will be frustrated (DES, 1978: Para 9.1).

Aspects of the Warnock Report gave rise to the Education Act, 1981, which attempted to address the report's recommendations. The 1981, Education Act also saw the involvement of parents increase within the inclusion agenda. It gave a duty to the local authority to consult and work with parents.

Parents could request a formal statutory assessment of their child where their needs could be legally identified. Parents could be involved in all annual reviews. They could also appeal against Local Education Authority (LEA) decisions and have their views taken into account in discussions concerning placement in special or ordinarily schools. Parents were also given power to have the rights of appeal to local appeals committee, and also the Secretary of State for Education and to have access to tribunals if they disagreed with decisions. Up until this moment it really was a case of 'school knows best' and parents did not question or have the avenues to question decisions.

In 1994, parents' rights and involvement were strengthened with the publication of the SEN Code of Practice. It was the clearest and strongest

affirmation of parental rights and the need to work in partnerships with them. To help enable this to happen in each school had to appoint a SENCo.

Within the 1994, Code of Practice, it stated that parents should have information on the school's SEN policy. They should also be provided with information on the support that their child would receive. It highlighted the need for parents to be encouraged and involved in assessment and decisions surrounding their child. In addition the local education authority were charged with providing information on services that were available and accessible to each individual parent; this included information on local and national voluntarily organisations. Arrangements were also made for recording and acting on parental concerns and for gaining parental views. (DFE 1994:2.33) This was a monumental shift in placing the onus on the schools to ensure parents were fully involved with the education of their child.

The closer that the parent is to the education of the child, the greater the impact on child development and educational achievement (Fullan, 1991:227).

In the White Paper, 'Higher Standards, Better Schools for All' there was a commitment to further involve parents, 'put the parents in the driving seat for a change' (DfEs, 2005a:1). However, what is true then and is true now is that some parents will grab the steering wheel and others will be left on the pavement, (Leeson, 2007). More confident parents will drive the agenda and articulate what they actually need. The ones who know how to make the system work for them will seize this opportunity. However, there are lots of other parents who do not know the agenda exists and others who do not want to be involved (Bank, 2007). A lot of parents want to entrust the child to school and let them get on with it. They may not have the time, interest or confidence to want to know what is going on.

Spring boarding to current times: the Children's and Families Act, 2014 and the New Code of Practice, 2014 both promote parental involvement and rights. However, the concept of parental involvement is still proving hard to achieve, as

one commentator suggests,

Despite all the fine words about working with parents, there is still a velvet curtain between home and school (Mettler, 2000:151).

We need to question, why? Using Bourdieu's work on capital (1977, 1983) proves very useful to understanding the degree in which parents are involved and the 'power' they hold within a school environment to help influence decision and changes for their child with SEN. If parents have greater capital the stronger position within the school environment they hold. As each capital aspect can secure a return on its investment, (Bourdieu, 1983).

It is quite clear that the more aspects of capital as defined by Bourdieu (1983) that you possess as a parent the more you can navigate the complex SEN system. My own experience highlights this. I had the knowledge, qualifications, experience, power, social networks, and the correct linguistic currency to put myself in a position where I could state that a particular school was not able to meet my child's needs in order to secure an out of county residential provision. I had consciously manoeuvred myself into a position where I was the decision maker on behalf of that school. I constantly reflect on the trajectory of my own journey and feel saddened that others are not in such a privileged position where they can influence decisions made about their child with SEN. Capital continually transmits and perpetuates social inequalities. This is an area that needs to be addressed if parents are to be involved. Work needs to surround how we can hear the voices of those with less currency, and what can we put in place to help promote all parent's views about the education of their child with SEN.

Even though it is apparent that historical conversations show a significant drive over the last 30 years to forge and strengthen the link between home and school. It could be questioned that the focus is wrong and the drive has been just words on pages, rather than actual practicalities by training professionals with specific ideas as to how to get those with less capital involved so they feel more valued

and respected. This reinforces the notion that I have previously highlighted of the misidentification of focus, Edelman, 2001. The need for value and respect is not a new concept. In 1971, Rawls, considered *self-worth* to be fundamentally important for all society members. A drive for self-worth should impose limits on the amount of inequalities that a society should accept. The idea should be that a person has a dignity and self-worth that social structure should not be allowed to violate. It starts with the basic principles of fairness and valuing each individual. Inequalities in wealth and social position are inevitable but it needs to be socially arranged in such a manner that it benefits the worst of groups and gives them self-worth.

Alongside value and respect comes trust. Within the Removing Barriers to Achievement, the Government's strategy for SEN, (2004) it highlighted the need to improve parent partnership work. In particular it discussed building parents confidence in mainstream education. The document stated that at this time there was a, 'culture of mistrust.' (DFES, 2004:79) It indicated that inclusion would only be successful when parents felt more confident and trusting of the system. Despite the Removing Barriers to Achievements guidance document (2004) focusing on parental confidence: parental confidence was still an issue in 2008.

In March 2008 a study was conducted regarding the lack of parental confidence in the special educational needs' system. The outcomes were highlighted in the Lamb Inquiry, (2009) into special educational needs and parental confidence, which was commissioned by the Secretary of State at that time. In his research it highlighted that they had encountered some of the happiest parents and angriest parents.

The Lamb Report discussed the need for effective communication and empowerment of the parental voice. It highlighted the need for good, honest relationships where trust, value and respect were underpinning, guiding principles. This is reverberated in Putnam's work (2000). In his research across 35 countries he noted that social trust had declined resulting in less social participation. Even though Putnam's work used social participation indicators

that were outside of an education setting it clearly demonstrated what happens when trust is diminished; resulting in lack of engagement in public affairs such as voting, town or school public meetings, lack of engagement in community organisations and volunteering. This mirrored what was happening with parental involvement in the late 2000s in the English education system. He set the debate alight on social capital as he argued for raising the importance of connectedness amongst people.

The need for social networks and the norms of reciprocity and trustworthiness that arise from them (Putnam, 2000:19).

This needs replicating in the SEN system in our schools today. It would seem prudent to see it as a collective understanding that society makes sure that everyone feels included in everything that happens and respects the tenets of utilitarianism; where contentment and happiness and respect for all should be our starting point for getting parents involved (Layard, 2005). This lack of respect and trust can arise unintentionally by the discourse or processes that are already in place within our school systems; including capital and power.

I have suggested that power is unevenly distributed depending on the capital you hold (Bourdieu, 1983). Teachers may have power that they did not realise that they had. Professional knowledge and a location within the school give them a position that parents and students may find intimidating. Young sites Foucault, and suggest we should look beyond an understanding of power as dichotomous in being a model of dominant and subordinate groups, but instead look at those who exercise power by their own actions, 'simply by doing their jobs and living their lives and not understand themselves as agents of oppression' (Young, 1990:42).

I think if you were to ask any of my colleagues that I have worked with over the years, if they thought that they were agents of oppression just because of the role they hold they would be shocked. Educational professionals can underestimate or be oblivious to the impact that they have on others. On the contrary, some might be completely aware of the power they hold.

Power is not fixed but is instead fluid. Foucault's interpretation of power can be viewed as fluid, interchangeable and generated between the different interactions of individuals and groups rather than seeing power as an absolute entity owned by a person.

What I am attentive to is the fact that every human relation is to some degree a power relation. We move in a world of perpetual strategic relations (Foucault, 1988:168).

This is an important concept as the power that has been described in my case studies changes depending on whom the parents are interacting with. This will be explored in more detail in my findings section. This indicates that power is far more complicated than just a structuralist approach where the emphasis is on power being of a more dispersed and fixed nature (Thompson, 2003).

However, is it the 'power' of other agendas that is putting a strain on teacher/parent relationships? Could other more 'powerful' forces and agendas be driving teacher's foci? Mittler's (2006) work hints that raising standards and achievements during the late 1990 has had a devastating effect on parent/teacher relationships, as the focus has been very much data driven, and ignoring parents. Our market-led system has relied heavily on data and league tables. An increase in marketisation of education could be seen as resulting in the influx of a strong form of managerialism, which in turn, arguably, does not support inclusion and parental voice. Managers within schools increasingly face the dilemma that giving too high a profile to SEN work may not match with concerns to promote a market image based on a high level of pupil achievement (Bines, 1995). Schools are too busy trying to do well in league table resulting in many schools ignoring a more equitable, coherent and humane policy for students with SEN: diluting inclusion and parental voice (Tomlinson, 2005). Baroness Warnock echoes this where she describes things as getting, 'far worse from 1988 onwards[...] (for children with SEN)[...] who [...] were not going to help the league tables,' Select Committee on Education and Skills Third Report, 2006:section 3).

This issue of assessment and data in relation to inclusion will be explored in more detail in the next section.

Tensions exist between ideology and practice. Barton, in *The Politics of Education for All 1995*, reinforces these ideas and shares concerns that we do not have a free market in which to promote an inclusive society as we have significant interventions from Government in terms of the curriculums, assessments, league tables and also the use of quangos such as Ofsted. As Bottery puts it, 'it is a paradoxical mixture of a free market liberalism and central autocracy' (Bottery, 1992:4). This creates huge tensions. Could the rhetoric and the reality be attributed to the magnitude of the task, and having too many competing factors within an educational setting; one being the introduction of league tables?

Or is it because the relationships are strained before they start? Getting off on the wrong foot. As the parents bring all of their historic conversations and experiences that they have had with many professionals and previous teachers and could be in a volatile and highly emotional state (Norwich, 2013). I know as a parent of a child with SEN I have felt at times exasperated with the system. I have been highly emotional and just burst in to tears when I met a new SENCo as I was just so exhausted with having to tell my story again.

The education profession needs to consider their attitude towards families and how they relate to them. A true partnership is a process rather than a destination, it is a journey undertaken as an expression of certain values and principles (Laylard, 2005, Mittler, 2006, Putnam, 2000). A true partnership, as in any close relationship implies mutual respect based on a willingness to learn from one another, having a sense of common purpose, sharing of information and decision-making and some would add the sharing of feelings. It is important to invest time and energy into this, as parents are critical to their child's success, 'Parents are children's first and most enduring educator' (Mittler, 1995:155).

What is clear is that we have policies in conflict. On one hand it is trying to promote parental involvement and parental rights yet on the other tensions exist from national legislation related to what and how we deliver the curriculum; how and what progress we report on and the current assessment regime, coupled with monitoring expectations from Ofsted (2012). In addition to this, how much capital a parent holds all has a dramatic effect on our inclusive practice and a schools desire to involve the parents of children with SEN or the parent's ability to be involved. The notion of assessment and accountability will now be further examined as it has had a dramatic effect on the shape of inclusion.

Multi-dimensional inclusion- the rise of assessment and accountability

The Education Act, 1988, (DoE, 1988) set out to create an educational 'market', which intended to allow parents to choose schools that reflected what they saw as important for their sons or daughters. In order for this market to work efficiently an index of performance was necessary so that parents could see which schools were doing 'well'. So whilst it promoted the parental voice, its main aim of this approach was to drive up standards; 'our vision is of excellence for all.' (DfEE, 1997:4). As a result the Government saw it necessary to create data collection points at different stages of a child's educational experience. Subsequently, the use of data is much more widespread and promoted by current politicians and policies. This has and is having a significant effect on inclusion.

A recent government document, DCSF, 2010, highlights the importance of the use of data,

High expectations followed by effective assessment and well targeted interventions can maximise the progress of children with SEN (DCSF, 2010:8).

This would suggest the importance of assessments in today's educational system.

Poor performance for those with special educational needs has also been highlighted at a national level in the same government document 'Breaking the Link Between Special Educational Needs and Low Attainment' where it states, 'indeed the SEN gap at key stage 4 has widened over the last three years' (DCSF, 2010: p10). In addition low standards for SEN has been reported in the national papers,

Just 20% of children with special needs leave school with 5 decent GCSEs, compared with 66 % of their classmates. According to data pupils without special education needs are more than three times as likely to reach the standards expected for their age at the end of secondary school (O'Brien, 2011:14).

All of this seems to be at odds with the initial intention of the Government in 1988 of using a free market to raise standards for all. An unintentional consequence has occurred where the focus has been on the majority of students rather than the minority of those with SEN:

We find that the use of national tests for the purpose of school accountability has resulted in some schools emphasising the maximisation of test results at the expense of a more rounded education to their pupils (DESF, 2008:208-3).

The question that needs to be asked is, 'what effect does this have on inclusion?' The focus on achieving as many 5 A* to C grades at GCSE at Key stage 4 at age 16 was reinforced in an article, 'Schools Focus Attention on Middle Ability Pupils to Boost Results' (Mansell, 2010:12). Unfortunately, it is these results, which have been put into league tables to allow parents and students to make their 'informed' choices. So naturally, if you were a school where results matter, the focus would be on the majority rather than the minority. Mark Baker, President of the Associate of Teachers and Lecturers (ATL), stated:

There should be no place for an ideology where it doesn't matter that children are different and learn in different ways, a ideology which does not recognise our different needs. School should not be forced to focus only on those who provide the best results, to the exclusion of others (Baker, ATL conference, 4th Sept 2014).

Inequalities are further promoted by the assessment regime. Assessment conflicts with the wider neo-liberal strategies that are taking place today in our education sphere. By fragmenting schools into individual traders it can lead to greater exploitation upon human resources. As what is considered valuable is favoured and the rest sacrificed. Those who can get the highest results are favoured against those who cannot achieve academically. This reinforces inequalities. This reinforces the disabled person identity and the inclusion discourse. In addition the SEN student is at risk as having less skills to operate in a neoliberal landscape as less attention, time and energy and resources are put their way.

As our GCSE system works on a comparative assessment methodology, it also means that the young people are constantly comparing themselves against another person of the same age within the same year group. Such comparisons in the difference of ability can lead to an inclusive world where you are using comparative data to segregate e.g. it enables and legitimises the differentiation, hierarchical comparisons and judgments made of students. This allows for differing pathways leading sometimes to different educational institutions for post-16 education. So, if you have a SEN your disabled identity is further being constructed due to this comparative assessment regime.

Another unintentional consequence of league tables might be the tests themselves. What do they actually measure and how valuable are they for those with SEN? And what impact do they have on inclusion? By having assessments, such as GCSEs that codify everything, are we potentially turning learning into a straitjacket experience and ignoring the humanistic and social-cultural factors that affect learning? Strathern (2000) suggested that by decoding everything we are in danger of driving the assessment process to the ground as it becomes increasingly meaningless, as its function is not fit for purpose. This is also true of attaching more meaning to it than it can carry. As Gould reminds us in his work, about the danger of investing more meaning into a number than it can hold, the

process known as 'reification'. As he points out:

We passed through this world but once. Few tragedies can be more expensive than the stunting of life, few injustices deeper than the denial of an opportunity to strive or even to help, by a limit imposed from without, but for falsely identified as a lying within (Gould, 1981:6).

To our peril we could be giving too much meaning not only to the responses but also to the criteria of the assessments themselves. Inappropriate assessments could have a devastating impact on inclusion, as tests often capture only a few aspects of what makes up intelligence or systems of ability. Many assessments use a single score; this is particularly true of the GCSEs. This could seem inadequate to describe the multi-dimensional nature of human intelligence. A parent could see this as rather insulting to their child's intelligence with or without SEN.

Another concern that needs to be highlighted is that individuals with similar test scores can vary so greatly in what they really are about. Two students may have the same scores but have such different learning needs, personalities and talents. It could be that we are approaching assessment with such naivety as individual's process and perceive the world in completely different and unique ways. In Kluth's work she suggests that assessments give little attention to social, emotional, moral, creative and practical intelligence and natural and radiant thinking. In 2009, she wrote about assessment of students on the autistic spectrum:

For many individuals on the spectrum, especially those without reliable communication, there is no test that can measure what they know and can do. Therefore most of the instruments used in evaluations measure autistic symptoms as much as, if not more than, abilities (Kluth, 2009: 64).

Today's assessments arguably could be seen to focus on what students cannot do rather than demonstrating what they actually can do. For example, a student who has autism, might have a particular fixation which affects their

performance, (Kluth, 2009). Ian has a fixation with Star Wars. Within his own area of interest he might hold huge amounts of known vocabulary and knowledge and definitions of the world, which will not necessarily be reflected in an assessment such as a GCSE. In fact he might score very low indeed on certain tests yet be a very skilled within his own area of interest. This reinforces how certain types of capital are considered more important than others. If we valued Ian's knowledge surrounding Star Wars then he would have more capital to trade with (Bourdieu, 1983) instead we do not value it within the current GCSE assessment regime. Frankie's' capital is arguably diluted in comparison to his 'able' bodied peers.

Heron's (1996) work seems to hint that we have a system in conflict as on one hand we want to develop the thinker, and develop self- worth yet on the other he sees us as having a rigorous assessment culture which is narrow, tight and technically focused which does not celebrate the student's strengths and particular skills therefore leading to a less inclusive school community. Boud's (1995) work, goes further and suggests that the assessment process is actually ruining the relationships between people and how an individual perceives themselves, as it deconstructs the student by focusing on what they cannot do; the deficit approach. As one of the parents stated, ' why are we putting him through these tests, they are not right for him and are creating unnecessary pressure for him and us'.

I would propose that the results of *any* assessment could and do redefine students' self-identities as the poor results could create many negative predispositions; it could lower aspirations and build a self-fulfilling prophecy of low self- esteem and low aspirations, potentially further damaging inclusion for those with special needs or disabilities. This could also result in parents feeling as though their child is not valued in the school system. Reay and William (1999) write of the disturbing shift in how students and others view themselves as a result of test scores. One male student with SEN exclaimed when learning of his GCSE scores said, 'I am crap; always have been, always will be'. Reading John's story will also highlight the negative impact an inappropriate curriculum and

assessment regime can have on someone's wellbeing and self-identity. I would advise that it seems inappropriate to summarise a person's capacity and work with a test or number. It would appear that we are trying to assess individuals but assessing so little of what they are about. What effect does this have on inclusion and how the inclusion discourse is shaped?

It would also appear necessary to take into account the forces that affect relationships and their social space, 'field' Bourdieu (1999). I propose that all social arrangements are going to have an impact on the assessment outcomes. Bourdieu's work suggests that it is important to take into consideration the experiences and fields that the individual has passed through, 'habitus', (Bourdieu, 1999). The concept at an individual level means that one gains a system of acquired dispositions. These dispositions will affect how a person acts and how they respond verbally or non-verbally depending on their prior experiences and the field(s) that they have passed through. In addition, I previously mentioned the necessity of re-defining 'field' to include internal forces such as autism that is arguably out of the student's control yet his habitus passes through every waking moment and is shaped by it.

I would consider this particularly relevant when assessing students with SEN as to ignore their 'field' and 'habitus' and the way that it has shaped their reality of the world could be considered foolish, especially as their experiences could be very different than those without SEN. Yet, it can be argued, that is exactly what we have done by assuming this technical, narrow assessment regime for school national testing. It therefore begs the question- Do we need to have a more holistic approach to our assessment arrangement so that we better understand the students to help us improve inclusion? If we did, could it result in the learning experience holding more value and ironically producing better outcomes and resulting in a truly inclusive school? As currently it could be argued that the 'atomised' and 'quantifiable' approach makes little reference to the importance of the humanistic paradigm, and is reinforcing the notion of inequalities not inclusion (Wallace and Hoyle, 2005).

However, understandably test scores generated from this assessment regime seems rather seducing in the complex world of students with special needs: 'They offer the immediate and tempting appeal of a seemingly exact, defined judgement of a student' (Kluth, 2009:10). Unfortunately, it is these results, which have been put into league tables to allow parents and students to make their 'informed' choices.

My next section will analyse inclusion and its current position; where we are now

Multi-dimensional inclusion- current position

Setting the scene.

In very recent times there has been a radical, legal movement towards changing the SEN system in England. Potentially, it could be the biggest shift of our time. The Department for Education claims that the changes will be the biggest reforms to SEN provision in 30 years (Gille 2012). These changes have come about, conceivably, due to the deficiencies of our current system; for example, as previously mentioned, in 2006, a Select Committee on Children, Schools and Families reported on special educational needs and highlighted the concerns rose by parents about their lack of confidence in the SEN system. Brian Lamb, Chair of the Special Educational consortium, was asked to do an inquiry into parental confidence following the Committee's findings by the Government at that time. The Lamb Inquiry - Special Educational Needs and Parental Confidence' (2009) concluded:

1. A clearer focus on outcomes for those with SEN is necessary
2. A stronger voice for parents is vital
3. A more strategic local approach is needed
4. A more accountable system
5. A national framework

Within these main headlines there were a total of 51 recommendations. On the same day the publication was released the BBC News website ran a piece called 'Special Needs Parents 'Need Help'' which stated that:

A government-commissioned study by Brian Lamb says that a significant number of parents are not satisfied with the help they receive. In response, the government will promise measures including a national support helpline and clearer information about rights to support. Parents have complained that feel they have to fight the system (BCC News, 2009, Dec 16th).

In addition there have been many other reports written about specific aspects of SEN provision. One being an Ofsted review of SEN, 'Special Educational Needs and Disability Review- a statement is not enough', which was published on 14th September 2010. The Labour Government commissioned this review. The remit of the review was to evaluate-

How well the legislative framework and arrangements were serving disabled children and young people and those who have special educational needs (Ofsted, 2010:3).

It focused on,

The accuracy and appropriateness of identification and assessment across settings and areas; expectations about potential; access to good educational provision and other services tailored to meet their needs; improvements in opportunities; and the progress made in preparing disabled children and young people and those with special educational needs for the future (Ofsted, 2010:3).

Its main conclusion was that hundreds of thousands of children have been wrongly identified as having special needs. The report stated that the term "special educational needs" was used too widely. Around half the schools and early years' provision that they visited used low attainment and relatively slow progress as their principal indicators of a special educational need. Inspectors saw schools that identified pupils as having special educational needs when; in fact, their needs were no different from those of most other pupils. They were underachieving simply because the school's mainstream teaching provision was

not good enough, and expectations of the pupils were too low:

In some of their visits to schools, inspectors met pupils who were provided with significant additional support whose needs could and should have been met by appropriately differentiated teaching, good learning and pastoral support earlier on (Ofsted, 2010:3).

Ofsted found a culture of excuses was common as was a lack of drive and ambition to ensure that the pupils grasped every opportunity to learn. The review also emphasised that just because you had a Statement it did not mean that your needs were being met. In addition the review noted how desperately complicated the legislation, guidance and systems surrounding special educational needs had become over the past 30 years.

It was quite clear that in the successful, outstanding providers there were clear outcomes, with a culture of high challenge, high aspirations and an attitude of 'we can achieve' where clear lines of accountability and exceptional quality assurance monitoring processes were common place. What was interesting was that a successful approach to SEN was not determined by locality but appeared personality driven. This will be explored further in my findings.

The report concluded with six key recommendations:

- A focus on the quality of assessment will improve the quality of outcomes.
- The right support must be available when and where it is needed.
- Schools should focus on improving teaching and pastoral support early on so that additional provision is not needed later.
- Specialist provision needs to be developed strategically so that it is available regardless of where children receive their education, for example in a maintained or independent school, an academy or a college.
- Legislation should be simplified so the system is clearer for parents and schools. Schools should stop identifying pupils as having special educational needs when they simply need better teaching and pastoral support.

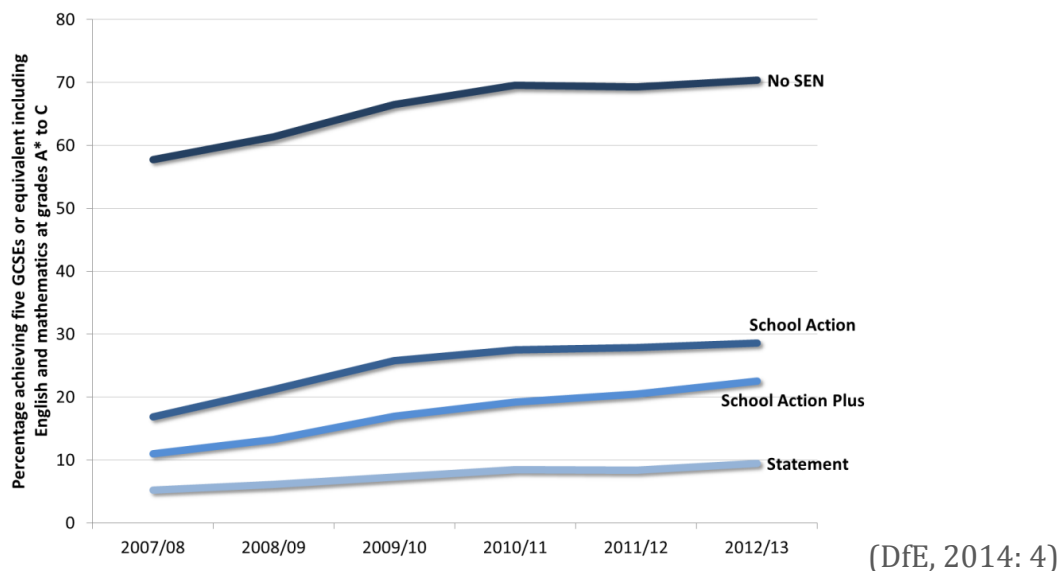
(Ofsted, 2010:42)

This report was instrumental in ensuring a shift in direction for change.

Change, could have also been attributed by a desire to improve outcomes and life chances for the current 1.4 million (DFE, 2014) who have been identified as having a special educational needs and/or who are disabled. As figures suggest that currently life chances for this group are disproportionately poor. One example is the table over the page highlights the difference between those students with SEN and those without achievement of 5 A-C including English and Mathematics: a key performance measure for all year 11 students across England.

Percentage of pupils achieving 5+ GCSEs at A*-C or equivalent including English and mathematics by SEN status 2007/08 to 2012/13

This shows that the performance of pupils with SEN has improved over the time period but generally at a slower rate than for pupils without SEN.



Even though analysing such data would demand knowing several key factors about the composition of each student cohort it is clear that there is a marked difference that, rightly, was noticed. Questions needed to be asked and solutions needed to be found.

In addition, many children and families would argue that the system was too bureaucratic, bewildering and disjointed and many would say that they felt frustrated by the lack of the right support and low expectations of the school. (Norwich, 2013). Some parents felt they were forced to negotiate each bit of their support separately (DFE 2013). These drivers gave way to the government holding an open consultation called: ***SENDS Green paper: children and young people with special educational needs and disabilities***, (DFE, 2010). To inform and shape the ways forward views were called for from anyone with an interest in SEN and disabilities in England. This consultation period ended on the 15th October 2010. The aim was to build the future plans based on knowledge and experience from professionals from health, education, social care, representative bodies and families. In total there were 1821 responses to the 6 questions that were asked:

1. Are the SEN and disability statutory frameworks – including the SEN statementing process – helping children and young people to get what they need? If not, what changes could help?
2. How can we identify children's special educational needs earlier, and make sure that they get the support they need as quickly as possible?
3. How can we improve the processes for special educational needs and disability – in schools, in assessments, and across all services – so that professionals can spend more of their time with children and their families?
4. How can we ensure all schools and colleges have high expectations for children and young people with special educational needs and disabilities, including their future potential and contribution to society?
5. How can we improve the choices of schools and services available to parents and improve opportunities for them to be involved in decisions that affect their family?
6. How can we improve the transition from school to adult life for young people with special educational needs and disabilities and the support provided for their families throughout?

The breakdown of those who responded were as follows:

Total responses to call for views: 1821

Respondent group	Number of responses	
Parent or carer	731	40%
Local authority	251	14%
Head teacher or teacher	169	9%
SEN co-ordinator	95	5%
National voluntary organisation	81	4%
Children's services	74	4%
Consultant or professionals	69	4%
School or college	67	4%
Local voluntary organisation	65	4%
Educational psychologist	42	2%
Governor	35	2%
Academic	32	2%
Professional association or union	22	1%
Parent partnership	21	1%
Child or young person (Their views were mainly represented by some of the organisations above)	2	0%
Other	65	4%
Total:	1821	100%

DFE (2010) Green Paper: children and young people with special educational

needs and disabilities- analysis of responses to the call for views: 8)

The response was poor; especially when you consider only 731 parents/ carers responded when there are a recognised 1,492,950 (DFE, 2014) pupils and young people with SEN and /or disabilities. It is also surprising to think that only two children independently shared their views. Was this because they knew nothing about it? This goes back to Bourdieu's (1993) work on capital. If you do not have knowledge in terms of capital how can you help shape, change or influence decisions for your child with SEN or if you are the one with the disability or need? Did any parents or children/ young people know about this?

However, the headlines that came out of the initial consultation were that people found the statutory framework process too bureaucratic; that the identification of children's needs needed to occur as early as possible; that there was a need for improving SEN training for teachers and practitioners; a need for a more joined up, cohesive approach between agencies and professionals; a need to involve parents and children more; a need to be more outcome driven and also an improvement in resources. What became abundantly clear was a necessity for a shift in culture about how SEN was approached through a legal framework.

The document that was subsequently published, ***Support and Aspiration: a New Approach to Special Educational Needs and Disability - A consultation*** March 2011; included outcomes from the initial consultation; parental control, learning and achieving, preparing for adulthood and services working together. The publication marked the start of a four-month period of consultation that ran from 9 March to 30th June 2011.

In May 2012 ***Support and Aspiration: a new approach to special educational needs and disabilities - progress and next steps*** was published. It reported on progress of the Green Paper and outlined the next steps.

The Queen's speech echoed the need for change and on Wednesday 9th May 2012 at the House of Commons the following was delivered:

My Government will strive to improve the lives of children and families. My Government will propose measures to improve provision for disabled children and children with special educational needs. New arrangements will be proposed to support children involved in family law cases, reform court processes for children in care and strengthen the role of the Children's Commissioner. A draft Bill will be published (Queens Speech, 2012).

SEN Legislation was changing. In February 2013, the Children and Families Bill was introduced to make changes to the law; which would be necessary for the Green Paper reforms, Support and Aspiration: a new approach to special education needs and disability, March 2011 to be enacted. In March 2013, to compliment the Bill: draft regulations and guidance were produced called an 'Indicative Code of Practice', which provided more detail about how the law would work in practice. The Children's and Family Bill passed through the necessary stages of the Houses of Common and was passed as an Act following royal assent on 13th March 2014. It came into effect September 2014.

Thoughts about the SEN legislation and our current position.

The Children's and Family Act, 2014, can be seen as a direct response to the coalition government commitment towards improving services for vulnerable children and young people due to the inadequacies of the system aforesaid. Arguably, the aim of the Act was to break down the perceived complexities, which surround the SEN system today, and to ensure teachers, healthcare, workers and social care all work together. Questions arise as to the how the Act will be played out and the impact it will have on real lives. Edward Timpson, Children and Families Minister, is convinced it will have a measurable impact:

The Children and Families Act is all about reforming services for vulnerable children - reflecting this government's deep determination to give every child, whatever their start in life, an equal chance to make the best of themselves. We will reform the system for children and young

people with SEN, including those who are disabled, giving children, young people and their parents greater control and choice up to 25 (DFE, 2014:2).

However, I would suggest that a negative ontology surrounding 'disability' and 'need' is reinforced by legislation of this nature. Legislation has not only given rise to this Act in recent times but also as I have highlighted earlier, equality legislation: all with the aim of giving more power to children, and young people with disabilities and readdressing inequalities that already exist within our system. Legislation is used to compensate for inequalities and by default promotes a discourse of 'ableism'. In other words there is an ideal that we are trying to aspire to (Oliver, 1995; Bank, 2007). Laws such as the Children and Family Act, 2014 with the supplementary New Code of Practice, causes 'disability' and 'need' to be codified by the law, repositioning one's understanding of it; sometimes detrimentally. Campbell considers our law surrounding disability as being 'malignant' (Campbell, 2000:2). This will be looked at further.

Identifying children and young people with special educational needs and disabilities

A local authority in England must exercise its functions with a view to securing

That it identifies

- (a) All the children and young people in its area who have or may have Special educational needs, and
- (b) All the children and young people in its area who have a disability.

(Children's and Families Act, 2014: section 22).

The above and The New Code of Practice, 2014, as stated at the start of this chapter, outlines the need to categorise need or disability. This recreates what society comes to understand about disability and need. It becomes part of the fabric of society without being questioned by swathes of people, especially those

whose lives are not touched by SEN on a daily basis. This was further highlighted when those whose lives are touched by SEN scarcely responded to a questionnaire about disabilities and need in the English System; as aforesaid only '2' children and '731' parents/ carers responded to a national survey, (DFE, 2010:18). Campbell's (2000) work highlights the danger of legislation by exteriorising an 'unthinking' disabilities discourse in the name of solving inequalities.

Foucault explains:

The 'unthought', for whatever name we give to it, is not lodged in man like a shriveled up nature or a stratified history; it is in relation to man, the Other, the Other that is not only a brother but a twin, born not of man, nor in man, but beside him and at the same time, in an identical newness, in unavoidable duality (Foucault, 1994:326).

Campbell's and Foucault's 'unthinking' concept needs to be challenged. As I consider that disability is always present in thought, by default due to the 'ableism' discourse, as whilst we strive for what is normal and human at the same time we are addressing what we do not want. I would argue that disability and SEN laws are in a direct response to a discourse of Ableism and the drive for a desired 'norm'. Looking deeper into Foucault's work the 'other' he describes in the previous quote, can be produced in a host of 'liminal spaces' (Thornton, 2000) and can change depending on how the 'Other' is being interacted with and when. The 'Other' can produce undesirable outcomes and can manifest itself in a variety of discourses such as, 'disability hate' or 'disability oppositional' or 'disability embarrassment'. This can be seen in terms of how someone without SEN responds to someone with SEN e.g. three years ago whilst taking a group of young adults with profound learning disabilities on a trip, the bus driver said, 'I do not want people like that getting on my bus.' Other ways can manifest themselves by people looking, laughing, and feeling uncomfortable, talking to the 'able' bodied rather than the 'disabled'. The latter is a frequent occurrence for my child: even by family members who adore him. If they do not understand what he says they automatically look at me to make sense of it. Legislation can, therefore, have an unfavourable effect on how we see the world unconsciously

or consciously.

In addition this 'terror' or 'panic' or 'embarrassment' rarely enters the legal system domain- they are excluded from legal enquiries and are not codified, (DDA, 1995; Equality Act, 2010, Children and Families Act, 2014). But yet, it is these sorts of examples that create a very negative ontological position for those with disabilities and /or need. It is these sorts of responses from others that can cause serious damage to the way someone feels about themselves and how we promote inclusion. It can be attributed to how society has internalised and externalised the new laws. The question of the value of legislation needs to come to the foreground. Questionably, law is preoccupied with the deficit model of disability. It reinforces what it means to be 'able', 'human', under the discourse of by talking about rights and equalities measured against the 'benchmark man', (Thorton, 2000).

Within our neoliberal society the practice of freedom is critical and an inherent right. Freedom penetrates our policies and practices and it is a barometer in the measurement of how civilised our western society is. This practice of freedom has been seen as a source of emancipation promise to address social inequalities so everyone can practice freedom, (Brown 1995:7) but freedom has been modified and codified by legislation. This is the paradigmatic embodiment of legality in other words whilst we are aspiring to be normalised citizens we are not free.

Freedom can be seen as an 'autonomy' drive towards maximum potential for all by the performance of your 'choosing, desiring and consuming subjects' (Foucault, 1997:40).

To practice this,

The individual within the neoliberal welfare state must be an independent person in their own right who is as free in as much as he is the proprietor of his own person and capacities. The human essence is freedom from dependence on the will of others, and freedom is a function

of possession-society consisting of exchanges between proprietors (Macpherson, 1964:3).

This has also been highlighted in my previous mention of transferable capital, (Bourdieu 1993). This assumes that to be free and participate in a neo-liberal landscape you have got to have a certain skill set. 'Free citizens' must be able to self-regulate and control themselves, be the pilot of their own control centre. For some, if you are a disabled person or you have impairments this makes it harder to achieve. It would have to be questioned if disability and SEN legislation needs to be viewed through a relational perspective as opposed to an autonomy few point as it is apparent that some people would find it very hard to achieve complete autonomy of their own life as described by Macpherson. Or do we need to redefine what we mean by autonomy? If we saw legislation through a different lens would the legal discourse move and shift disability away from the deficit model? Arguably, the way it is at the moment minimally disrupts society so could be favoured by some (Edeleman, 2010).

Legislation also reduces individual identity in favour of group classification. "The disparity and difference of disabled bodies to an unity (Foucault, 1980b:117).

The Children and Family Act, 2014, writes about parents, in one group, children and young people in another etc. The New Code of Practice discusses children and young people in 4 key headings:

- B) Social, emotional and mental health difficulties
- A) Cognition and learning needs
- C) Communication and interactive needs
- D) Sensory and or physical needs

(Code of Practice, 2014: 18).

And The Equality Act, 2010, is no different:

A person (P) has a disability if—

P has a physical or mental impairment, and

(1)

(a)

(b)

the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.

(Equality Act, 2010: section 6).

Categorising individuals tames the complex, unruly nature of disabilities. This does not allow for the fluidity and individualisation where disabilities crosses boundaries across time and events (Wendell,1996; Shildrick,1997). Is this done for containment? Arguably, it is a civilized workability: 'a regulated, legal liberty that produces practice of normality and rationality', (Campbell, 1996:4). Linton (1998), and Edelman, (2001), work adds weight to this thought process and both imply that there is a vested interest in keeping the status quo with the current legislation surrounding disabilities. A neo-liberal practice of 'unfreedom' appears to be taking place. A problem occurs as to what the Government does with those who cannot participate in a neo-liberal landscape. Hindess, work suggests three approaches:

- 1) Clear them away
- 2) Compulsion toward disciplinary techniques, such as normalization principles
- 3) Targeting external causes by creating a welfare safety net

(Hindess, 2000:11)

These dividing practices assumes abortion of those with disabilities or needs, rehabilitation of those with disabilities or needs, or metamorphosing into a nearly 'able body' person or becoming a deserving welfare recipient, (Hindess, 2000). The law, as I see it, plays an exacting role in promoting this. The law facilitates disabled individuals into permanent and distinct categories so disabled children and young people can be seen and accounted for (Foucault, 1976, 1994). In addition the law defines what is permissible enquiry and it establishes legal definitions of a disability. The law's reification of disability based on a deficit model reinforces the desire for the 'able body'. The law as it currently stands, I would advocate, reinforces negative perceptions about

disability.

Law in its very nature reorganises one's understanding of disability by performing an emblematic function. Powers are dominating what is disability law and subsequently effecting and shaping the inclusion discourse.

E.g.in the Equality Act, 2010, it states that you have a recognised disability if an effect of impairment is long-term

- (a) it has lasted for at least 12 months,
- (b) it is likely to last for at least 12 months, or
- (c) it is likely to last for the rest of the life of the person affected.

(Equality Act, 2010: schedule 1, Act 1).

So the above, for the very first time, indicates a disability does not have to be permanent. Law redefines what we come to understand disability to mean. It seems we have a juxtaposition; to practice freedom requires structures of opposition for freedom to flourish e.g laws. Maybe, the law

becomes the language of unfreedom, and is a vehicle of subordination through normalisation and regulation even as it strives to produce visibility and acceptance (Brian, 1995:66).

Furthermore, the recession might have caused individuals to ask about the perceived 'unproductive' nature of the disabled body and how contributions are made to society.

Neoliberalism is discomfited by the prophylactic measures that are perceived as impediments to the freedom to pursue profits (Thornton, 2000:19).

The Children and Family Act, 2014, is very clear that SEN must be outcome driven with a heavy focus on employability

However, law can also be perceived in a positive way as it can lead to positive images surrounding disability and give folks who have disability the chance to voice their opinions when they feel as though they are being discriminated against. It gives protection. If we analyse the rise in complaints this could indicate the laws are working for people with disabilities. Though, the complaints are still funnelled into 'classifications' through a paradigm of 'ableism'.

Legislation could even lead to resentment, 'Neo-liberal engagement with minority identities provokes a politic of resentment on behalf of the majority' (Thornton, 2000:20) The tide could be turning as 'able-bodied' people start questioning the laws and protections surrounding those with disabilities. The introduction of positive action, where preferential treatment is given to minority groups of society who have previously been subject to prejudice, is a controversial concept and I believe is wrong. I consider any form of discrimination to be inappropriate and further damaging to the Inclusion cause.

In addition the law can be seen as regulating the types of experience-disabled people have; it does not seem to appear to offer alternative perspectives. This was a concern raised by Mencap before the Children and Family Act became law:

Families up and down the country will be deeply disappointed. The government has promised the biggest reform of special educational needs for 30 years, finally bringing together health education and care support. This bill is a missed opportunity which will change very little for the parents, who currently face a long hard fight to get the right education and health support their child with a learning disability need (Scorer, 2013, Mencap Senior Campaigns and Policy Manager).

Moreover, this recent SEN legislation (Children and Family Act, 2014) is open to interpretation by whoever reads it. Arguably, each Local Authority will interpret

it in different ways having a direct impact on the provision that is provided in that county. There is no national framework stating what the provision, known as the local offer, should entail. Every time this happens it redefines what 'disability' and 'need' means for an individual and society. Recently, there has been the first judicial review of the Children and Families Act, 2014 known as the 'Warwickshire Case'. This involved two parents who argued that their county offer, was, 'deficient' and fell a considerable distance short of the statutory requirement.' The high court found Warwickshire Council's local offer unlawful in its response. This highlights the differences from county to county, it also highlights the capital the parents possessed to be able to fight the system (Bourdieu, 1993) but reassuring emphasises the legal backing that our new SEN reforms have for those in need or disabled.

The recent legislation should ask; what obstacles need to be overcome for each individual to reach their true potential and be that self-entrepreneur; and self-promoter in a neo-liberal landscape? I propose that it is not appropriate for those with learning disabilities to be merely passive recipients of legislation and put into a system, which is not adequately prepared for them. This would then again further suggest that the students would be unable to gain the necessary skills, due to poor provision and negative, deficit discourse that surrounds them, to be able to operate within a neo-liberalist inclusive model.

I would suggest that the transformation of legislation needs to be viewed through Foucault's notion of the continuity of the double bond and the relationship between the individual and totalisation. Foucault, in his work on governmentality, proposed that freedom and power are intrinsically linked with each other (Foucault, 1982). He demonstrates this by the use of the double bond of individualisation and totalisation - that is how a free individual within a nation is simultaneously linked with other individuals into a totality: that to be an individual means being linked to a totality. Legislation which is affecting inclusion through a neo liberal lens arguably hints quite strongly at this double bond, especially with the New Code of Practices categories of SEN, 2014.

My concern is that inadequately prepared provisions and poor decisions made in response to legislation, could promote an inclusive model of 'one size fits all' rather than seeing each individuals as unique. By default this would suggest that uniqueness is not being recognised and catered for. I would further suggest that it does not identify the student as a self -autonomous entrepreneur who should have choice, power and necessary skills to be able to influence their chosen educational pathway and later life decisions; key features of recent government documentation.

In order to achieve inclusion via legislation it would become necessary for those with learning disabilities not to be seen as a separate group (totality) of individuals but to be seen as individuals on a continuum of differences; moving away from the deficit model and negative connotations. As Wedell puts it,

If an education system is geared to meeting the diversity of pupils' learning needs, the inclusion of pupils with learning disabilities becomes just one part of this diversity, and so does not have to be separately justified (Wedell, 1995:10).

Then there would be a need for educational institutions to be flexible, innovative, and adaptable to meet a range of diverse individual needs rather than providing a monolithic system in response to law (Glaser, 1977). Seeing inclusion through a neo-liberal governmentality perspective (Foucault, 1978) would mean that the schools and colleges would become a flexible enterprise to meet individual needs. Diversity would then be seen as a fundamental feature of an inclusive society – where everyone has a stake. If we want to embrace uniqueness and the spirit in which the Children and Family Act, 2014, was written then there would be a need for a shift in society as it would have to change from being a collective body to being reorganised as a collection of temporary organisational structures that meet needs of individuals at a given point in time. If this was the case would not this be inspirational and truly recognising the uniqueness of individuals? Schools and colleges would then operate as enterprises attempting to cater for everyone (Simons, 2001). Inclusion in this way would indicate that everyone would have something in

common as they would all be working towards gaining the necessary skills to be able to be entrepreneurs and masters of their own destiny. This redefines, whilst reinforces, Foucault's notion of the double bond. This discourse would put an end to a narrow definition of inclusion. Inclusion would then be seen as a society with, 'no one outside'.

Concluding thoughts from this chapter

It would be exciting if we had a society with no -one outside, where everyone was embraced and uniqueness recognised. However, my readings and my own personal experiences indicated that this was just not the case and at the moment this is an idealistic vision. My research question aimed to seek the experiences that both parents and children had encountered at mainstreams educational settings:

'What does inclusion mean for parents with children that have special needs and what does it mean for the children themselves in today's mainstream schooling system?'

I wanted to seek how their 'need' was interpreted and the values and actions that surrounded it. I wanted to look at the notion of capital and how special education needs can affect the tariff, (Bourdieu 1983) resulting in reinforcing domination and subordination. I wanted to see how the management of self and how we display ourselves; our habitus - our deportment, our style, our body movement, what we say, and how we say it affected the capital we possessed. I aimed to seek how we value the 'disabled' body. I also, wanted to know the true human impact, unintentionally or intentionally; a discourse can have on the children and parents.

The next chapter documents the stories told.

Chapter 4

Stories Told

Ian's and Lisa's Story

Ian is a humorous, charming young man who is in his last year of compulsory schooling. He was identified as having autism when he was in reception class in 2004. Ian's mum is called Lisa.

Ian was born at full term following a difficult birth. Ian's early milestones were reached and everything appeared normal until the day that Ian had his MMR jabs. Both parents describe the almost overnight change in Ian following the injection.

But I would like to point out that at 15 months we did see a change in Ian- a definite change, and I mean an overnight change in him. If I show you some photos then you can make your own notes on this. I know you can look at the differences, this is Ian very young, and I would tell you that there are physical differences. I am adamant that the MMR caused Ian's autism and I would actually stand anywhere and say that (Lisa).

Lisa showed me the photos. There was a remarkable change in Ian's physical presentation.

Ian does have several specific problems associated with his Autism. He finds change in routine extremely difficult and becomes very distressed, then withdrawn if he does not understand what is happening. Ian can shut down if he is faced with stressful situations. He finds it very tricky to read other people's behaviours or comments, he takes everything personally and in turn this causes him pain. He is a little obsessive about his own agenda and will happily talk at length on his chosen topic. In addition Ian struggles with the concept of time and needs constant prompts about events and activities and timings of the day. He is sensitive to sound and likes to work in complete silence. He gets anxious if other students get a bit, 'loud'. Food is also an issue, trying to get him to eat different things Lisa reports as being a struggle. He is very limited in the foods he will eat. At one stage he would only eat certain sandwiches made from home.

Ian adores Star Wars; and is quite the expert on all matters related to this topic. He loves computers and gaming. Ian laughter is infectious and his eyes light up when he finds something amusing!

Early years

The primary school, which Ian attended, was set in a small, picturesque village in a rural part of the country. It had 30 students on roll. It was during his transition from playgroup to reception class that Ian's autism was picked up. He was hiding under tables, displaying echolalia with his speech and disassociating himself from people and things. What was memorable for Lisa at this stage was the narrow view that doctors had taken with her about Ian's diagnosis of autism. At this stage Ian use to walk on tip-toes and hand flap and make clicking noises repeatedly.

The GPs perhaps were not as experienced, as they should've been on the subject of autism as there were too many boxes they wanted to tick, and because Ian held a certain level of eye contact they initial sent us away. And as I said, if there is a spectrum then children are on it at different levels, therefore you were not going to display all the same things. I actually said to the doctor, you don't have to have spots to have meningitis (Lisa).

Lisa talks with vigour and energy about Ian's first experience in reception class; which was extremely positive:

He was in reception with a brilliant teacher. She had a great understanding and great patience, yes, lots of patience. At this school the learning support assistant was all also fantastic. She was with Ian for the whole time at this school.

At the time Ian's diet would consist of chips and ice cream. When I told them this they just said 'yeah that's ok, of course we can do that.' They just were not judgmental. They took it as it came. The Headteacher was also brilliant and he pulled out all the stops even though they did not have any funding for him. They completely understood. There were times when Ian would go to school and have a complete and I mean complete rage to the point where you had to hold him because you were afraid that he would injure himself. The Headteacher would sometimes just sit on the stairs with Ian to help him calm down (Lisa).

Lisa then describes the following two years as not being critical but not as successful as the reception year. This was because whilst the next two teachers

did not seem to understand Ian, Ian still had the support from the Headteacher and the same Learning Support Assistant.

There were two times when it went wrong at the school. In year 2 . The teacher was a Newly Qualified Teacher (NQT) and she did not really understand it. As a person she was lovely she tried to do all the right things but she was out of her depth. Then in year 3 there was one of the teacher that was not out her depth but I think she was just plain rude. I went in there one day because I wanted to talk about Ian and she did not bother to stop typing and look at me she just said that I was being overprotective. She had no concept of autism. So I gave a book about it I said to her please just read it, I said please read it so you'll have a better understanding. She said, she did not need to. What you want to know, as a parent is, is the person that is looking after your child actually understands it. If they have got no understanding of it then there is no point in Ian actually being there at that school (Lisa).

Lisa then speak about the fantastic fourth year and accrediting it to the teacher and the Headteacher.

What worked at this school was that they got a place for him to go and have time out. The Headteacher he was fantastic; he was very, very flexible. All staff if knew that if Ian needed time out to this room, then he needed to go. If there is going to be inclusion then I think that everyone should be made aware of what autism is. The last year at the school was brilliant again the teacher was absolutely brilliant (Lisa).

Ian cannot remember anything about this time. When he is asked he says:

It was such a long time ago that I can't remember anything (Ian).

Rocky Times

Following the small rural, village school experience Ian moved to another school. This was a large town school. This school proved problematic for both Ian and Ian's parents:

The next school-where do we start! Well it became increasingly more apparent that he was very behind. He was probably a year out of sync from his peer group. David was working away at the time and it became more and more obvious to him when he came back that Ian was growing away from the norm.

He was not happy there. These next years for me, was the most difficult period, because despite repeated asking, that they should forget everything

else and keep him on board with literacy and numeracy, and let him be involved with things that are ICT because he has it at home and he can get on with it they ignored me; he fell further and further behind. I volunteered to help in the classroom to make sure that he was doing it. We should not have to resort to that. It would not matter if Ian could not remember the kings and queens of England, but as long as he was able to read about it. Reading and comprehension and some arithmetic would be good...I know that no one is expected miracles, but there is no point in giving him geometry if you cannot do arithmetic. It's an inappropriate curriculum. Ian has been fed a lot of stuff that he is never going to be able to understand (Lisa).

It was difficult to establish one critical incident for Lisa as she deemed all the years that he was there as an unhappy experience. Ian echoed this view:

Fuck all went well; nothing went well there. The teachers were bossy and strict. She was impatient with people that had disabilities like me. I hated it. It was really bad (Ian).

Lisa continues:

They had no concept that you cannot make an autistic person come into your world- you have to try and understand their world. We're the ones that are all sitting here quite happy because we fit together quite nicely. It's Ian that doesn't fit in and they failed completely to grasp the concept of that. They took him out of lessons, they took him out of ICT, they put him on the Wii, they set up a thing called golden club which was meant to be some kind of reward thing, but I think that was behaviour based and not academically based... It was just foolish. It was lazy. Sometimes, in order to benefit their own schedules, it was easier to take Ian out, and had him sat along their side colouring. The staff used it as planning and prep time.

There are a lot of things that are blanketed over.

They even made Ian stand out in the rain. This support assistant was not with Ian for very long as I put in a few complaints. People said she was lovely and that she be devastated if we thought this of her, but I said I don't care if she is devastated I just want something sorted about it. She treated his behaviour as bad behaviour. She was impatient and lacked empathy.

Repeatedly I would ask that they spend time with him with basic numeracy, telling the time, literacy, and stuff like that. In fairness, because of the interventions of speech and language, Ian has come out okay.

In his last year there was one learning support assistant who was great-he cared. That was positive there. However, the teachers did not help. You can put a sign up and say 'inclusion' anywhere, but if it is really happening it is

a different kettle of fish. Anybody can put at the notice and say 'we do this' but I had to take them to task one day because Ian was going to the class room every morning and he would say 'morning!' and none of the kids answered him. And these were kids that he'd been to the previous school with. I said to the teacher 'he's speaking to them it would be nice if you could do a blanket thing where everyone speaks' and he was like, 'the kids make their own choices' and I said 'yeah and Ian made a choice to speak to somebody'. Everything was dealt through the SEN office; it was not dealt through the teachers and the school systems. This instantly tells me it's not inclusion. If you had a problem you did not go to a teacher, you went to the SENCO. If I went to the Headteacher he would refer me back to the SENCO (Lisa).

Happier Times

Ian then transferred to a large secondary school. He is still there today. In a sharp contrast to the previous experience Lisa and Ian describes this as being successful:

Ian accepts school now. His idea of a perfect day is when he's come home; nobody has played up in class. He likes all the teachers; he gets on well with all the teachers. When he had the Head teacher for science, he loved it. I said to him 'did the teacher come and speak to you' and he said 'no, I was getting on with my work'. When she was in there it was calm. For anyone with sensory difficulties you don't want noise in the classroom. It's been much better coming up to this school. He has coped better and he has improved. The good thing is, he has improved academically. The sad thing is, the legacy that was left from things that happened in the previous school is not good.

He sees himself on a par with his learning support assistant, because he feels like he can have a bit of a joke, and what I like is that he's not being affected by everything. We were walking past a teacher the other day and Ian said hello to him, and this teacher looked very surprised and he said, 'good morning Ian how are you?' And he said 'I'm fine thank you how are you?' And I thought, there are not many kids that would do that. And somebody else went past him one day and they said, 'are you alright Ian?' And he said, 'yeah thanks for asking'. He seems to have found a level that he can talk on. He doesn't relate to that many other kids and he cannot relate at all to bad behaviour.

What I like is that things get sorted out. Or if it goes wrong they try to make it better. Apparently this lad flicked him with a towel in PE, and he had done it on his backside. For Ian, it was not about being flicked with a towel; it was about where he had done it. For Ian that was wrong. He went up to the teacher and told the teacher that he had talk to the boy. The teacher

got it sorted. The other year, they had bikes in PE, and they did not know that Ian could not ride a bike, and they had to do this thing where they had to have a relay with bikes. Ian did not, and he just pushed the bike, but the teacher felt bad because they felt that they put Ian in a position and they apologised for it.

The only trouble that he has his PE is when its team games, when it's ballgames, and people will not pass to him because he cannot deal with it. He wants to be part of it but they don't want him to be, because he's not useful to them. We say to Ian that you were always going to encounter things in life that are going to be difficult. We cannot take things away but we can teach him how to deal with it. Sometimes people want to be in the background and don't have to always be included in what we perceive at included, which is okay. For example when they are doing Volleyball at school he might not want to be actually playing it instead he feels included by watching and supporting it.

In terms of the school the thing that has worked is that he has a place to go at lunch and break, which has given him a bit of independence. He hasn't had that before, he's been segregated. He is protected, he is happy, he now has his own friendship group, they are allowed to flourish in their own environment, and he gets extra help. Some teachers are outstanding with him, because if they see that there is something that he wants to do then they will really develop that with him; play on his strengths.

You need someone that properly wants to lead SEN in a school. You cannot just have someone that is doing it because it's easy work. Someone needs to have subject knowledge to be able to work with someone that is taking the subject, for example taking GCSEs. The support must be able to get up to that level. You should be passionate about being in a job that involves special needs and not just take the job because it fits well with the holidays and your children. I do feel as if we have enough support for Ian (Lisa).

Ian did not want to talk and got agitated with me asking him questions. So I stopped. He did, however, say that everything has gone well as this school. He exclaimed with increasing frustrating that he does not have good or bad days anymore and that everything was fine. He was obviously in a rush. Lisa then explained that today was the day that he had just got 15 star wars figures and quite frankly anything else was a distraction and a major irritation!

Archie's and Paula's Story

Archie is a delightful cheeky chappy who whirls around the place seeking and trying to make sense of the world around him. Archie's mum is called Paula.

Paula had a very bad pregnancy. She was very ill; she could not walk and could not stand. From three and half months of pregnancy Paula had to stop work until after the birth. Archie weighed in 9lb 5oz and Paula described the labour as 'hideous'. Archie was born by emergency cesarean

Paula realised that Archie was behaving differently than other babies of a similar age when he got to three months old. She describes Archie as stopping sleeping in the day, only sleeping at night time and being hyper alert all day long. Then when he was nine months old she describes the sleeping stopping at night time as well. As Archie got older, Paula describes his behaviour as becoming increasingly more different than other children around him.

He always had a sock and was always flapping it around, and always on the go. So I did not necessarily think that he had any conditions but I just thought that we had a child that was incredibly active and hard, hard work. Then when he started to talk, he very quickly started to talk and pick up language and use language in a way that I hadn't ever seen other children use language before (Paula).

Archie's use of language was very advanced for his age, saying words like 'campanologist': yet whilst he could speak his emotional intelligence was not developing at the same rate. Paula remembers that when she used to come home from work Archie would be devoid of any emotion.

I would come home from work having been out all day he would have no interest in saying hello to me or acknowledging that I had even walked into the room which was odd (Paula).

It was Paula's recounting her experience of Archie to a GP, which led to the diagnosis of Asperger's Syndrome.

Archie is now 11 years old and attends a local mainstream school. He was diagnosed with Asperger's Syndrome and ADHD and at the age of 5. He needs help to being able to process what he is being told and help to be able to stay on task, concentrate and focus.

Archie has fixations and they have been consistent since he was a toddler. He adores helicopters, aeroplanes, the army, and guns. However, he has a new fascination with drumming. Luckily, he has a summerhouse at the end of the garden where he plays to his heart content! He talks and reads about these things all the time and is constantly trying to learn about them. His obsession extends to using all of his senses. Amazingly, he can identify the type of helicopter that is flying overhead by the sound of the rotor blades before he actually sees it. He is very precise and interested about anything that is technical.

Early Years

Archie attended a mainstream nursery school in his local town. Paula describes this experience as rather unsettling and upsetting.

I have very a strong memory and overriding memory of just before he started school when he was at nursery and we did not have what I would call a positive experience of this as because every time we went to pick him up there was always a problem. I particularly remember an occasion when the nursery manager called me in to tell me that yes she did think his behaviour was different and there was something different about him. But she said she believed that in six months time whatever was wrong with him, he was going to grow out off. And I very, very, very precisely remember the meeting because I did not particularly think they had helped Archie at the nursery and I did not believe that he was going to grow out of it. What an odd statement to make (Paula).

Archie quickly pointed out that in fact he had attended both a nursery and a playgroup and had quite strong views on how he felt about each place. His memory was rather incredible:

I preferred playgroup more than nursery because it was just a nicer atmosphere. One teacher at nursery seemed depressed and she used to shout at me for biting my jumper. Then I got angry, and I was right next to my friend who cracked his head, and then she tried to blame it on me and then I took one of the Playhouse's doors off (thinking I was the world's strongest man) and I got sent to her office. I was always in her office. And they always used to tell you how to eat your lunch and in which order and they always used to make funny comments.

I went to the nursery a couple of times a week and for the rest of the week I went to playgroup. Playgroup was really good. That was great because they had nicer staff and you had loads of snacks. The teachers were really nice because they just let you do what you want, and in playgroup you just got dropped off, went for half a day, then came home and did what you want. It was fun (Archie).

It was during this time that Archie's behaviours were increasingly noticeably different than his peer group. Archie never seemed to be able manage social situations; Paula described him as always on the peripheral of something. However, he was always content to be by himself.

Paula remembers that nothing was ever enjoyable because it was such hard work and that she could never relax. She describes just popping to the shops to get a loaf of bread as being problematic and also Archie's endless running away.

It was only later life that I realised it was those horrendous bright lights and over sensory stimulation that for him was a complete nightmare but for me I thought I was just popping in to get a loaf of bread. But for him was a nightmare. So I did not go anywhere because if I did go to a shop he would scream.

He also kept on running away. He did not stop the running away until he was at least six I would say, five or six. So that would meant that I could not even go and sit down anywhere like on the beach or sit in the park and play together because all the time he ran away (Paula).

The experience of both Archie's behaviours and the nursery left Paula, her family and Archie worried about starting the next school.

The First School

However, Archie and family need not have worried as this school, in the main, was a positive experience for Archie. This school is a large town school. Archie stayed here for reception class, year 1 and 2. During year 3 they moved area and school but they came back when Archie was in year 4.

I would say that for that the time Archie was at this school we were incredibly lucky- apart from in year 1. What made it I would say, and even to the present day is having empathetic teachers. Teachers who realised and knew the difference between the problem; accessing things and seeing what was naughty behavior and what was autistic behaviour; because you can spot the difference. And it's not always easy but when you spend time with Archie, you do know when he is being willful and naughty and when there is an actually problem (Paula).

Archie had a good year in his reception class.

He had a reception teacher who was incredibly patient and interested in him and the things that he was interested in and pushed his interests and gave him opportunities to do that he was interested in to develop his interests and worked with TAs who were also empathetic. They recognised that sometimes they might be in the middle of a lesson and if he heard a helicopter that it was okay to take sit in playground for five minutes to watch it. It was also, the communication between home and school. We set up home school diaries, that has been a pivotal lesson of what works and what doesn't work. He has always had them and we have spent a lot of time every single day writing in those dairies (Paula).

Archie spoke fondly about the reception year.

I did enjoy it at reception because there were other kids who I got to make friends with who went to different nurseries and stuff. It was not fantastic but it was very good because there was still school work. It was a school it was not proper playing, it felt different. But I had lots of friends in that year (Archie).

The majority of the experience that Paula had in this school environment was positive:

The TAs and the teachers worked well together. He was given those opportunities to go off and do something a bit different. They had an acceptance that he was just a little bit different- but realised that he actually had a lot to contribute to the class. It was things like having the use

of a Sensory Room at the school, being able to go out and have some music therapy, and being given different opportunities (Paula).

However, Paula describes year 1 when it does not work quiet so well:

There was one year that did not work that well and I think that it was fair to say that that year the teacher really was not interested in Archie and was not that empathetic and really regarded him as a bit of a pain and a nuisance rather than properly accepting that he needed something a little bit out of the ordinary and that was not a successful year. That was just about managed (Paula).

Archie in a separate conversation with me echoes this and described the teacher as:

not understanding him (Archie).

It was whilst Archie was at this school, during year one, that Paula and family started the process of firstly gaining the ADHD diagnosis and then Archie's Asperger's Syndrome diagnosis. Paula describes the experience as quite a battle that left her feeling exhausted and poorly.

We did not have to fight for the ADHD diagnosis but we were 100% convinced- as was any other person who was medical who had met Archie were convinced that also he had Asperger's. It was harder to get this recognition but we felt that was important for his education, for us and for him, so we pushed for that and I would say that diagnosis probably took about a year. Because we had to go through assessments, speech and language, occupational therapist, education pyschologists, we had to go through the whole process. And we just had to be quite persistent.

I was still working full time. I did not very well manage it because at the end of year one or half way through Year Two I just became too exhausted and unwell. And took the decision of, because we were having so many doctors appointments and how tough it was at home, I just could not carry on working. And I think it was by the end of Year Two that I was going to think about dropping back and leaving my job but in the end I had to do it a lot sooner because I just could not carry on because it was such a struggle.

I would say that Year One was a blip it was not so happy and challenging. The teaching in Year Two, Three and Four just got better and better and better (Paula).

The Big Mistake

During year 3 Paula and her husband moved to a village, as they wanted a close-knit community for Archie to grow up in. They romanticised about Archie going to the park by himself and being embraced by the other folks who lived there. This meant a change in school for Archie.

We left whilst Archie was in year three, we moved house and changed schools. I did an awful lot of transition work over at the school before he started because of the very reason that I knew transitions were difficult. I went into a lot of meetings, and told them about all the things that had been successful and told them about all of the programmes that were in place. I asked them to liaise with the First School and I described at great length the things that were successful and what worked with him.

It was not a successful experience at all. His personality changed at home, he became very remote. He did not want to leave the house, he did not go out into the garden. He was very unhappy, he did not want to go to school. And previously he had never ever wanted to miss a moment at school; he begged us not to send him into school. The only thing that he liked was going on the minibus into school which was a change for him, he liked that. He was very, very unhappy. All the liaison comments that were coming home were very negative and not professional at all. We would get notes in the book saying that that other parents were complaining about him.

Through talking with him about things it became clear that things were not quite right, there was no support for Archie at playtime and during unstructured times and the impression I got- and I think that I am right from various meetings I had with people and that in fact with the head teacher- was that he was not properly supported and guided. And I think there was an inclination not to have a child there with the needs that Archie had. It culminated one day. He was so miserable and so unhappy that when he came home from school, I think it was the day after I had received that notes in the diary and top of that lots of other difficulties, he said that he wanted to kill himself. That was very difficult for us so he did not go back again. I did follow it up with the Headteacher I wanted to talk to him about how Archie felt and to make him aware. But I think that he was not terribly interested. He also said to me that he knew that Archie hadn't had had good teaching and if I was to hang on a year and send him back he could guarantee me good teaching the following year.

I felt angry that people did not want to help or were not doing anything to oversee his pastoral welfare. We did not know what to do but we took him out and we had nowhere to go for about three days (Paula).

This experience was traumatic for Archie.

It was just horrible there- they did not understand anybody. When you were supposed to be on the computer they did not even care so I just played games; they probably did not notice. I did not have any support from people. I was not understood. The teacher was even stricter than my year one teacher. She asked the class to draw a swimming pool and she said to me 'I want you to draw a better swimming pool or you'll be here at lunch'. It was the best swimming pool I could've drawn and she made work really hard. I felt lonely and isolated because I tried to play a game of football with the kids at lunch but they would not let me. And one of the kids threw the ball over the fence and blamed it on me and I ran away from the teachers and climbed up trees and stuff (Archie).

Archie moved back to his old school. The feeling of happiness was almost instantaneous.

Back to his old school

Archie was happy, the day he went back the class cheered. The day that he came back from school he immediately changed overnight back into that happy boy that we had known him to be. Fairly soon because we realised that the commute was intolerable and that we could not sustain and why on earth could we live where we wanted to live at that time if it meant two hours driving a day. So we then realised that we had to move back to where we had come from. This was a very expensive move; but were not thinking about the money we were just thinking we had to do what was right for Archie (Paula).

He had a fantastic end of that year and then a fantastic Year Four. He had lots of interventions programmes and lots of empathetic teachers.

We always felt really valued and really appreciated, also I gave a lot back to the school in return. I did all the PTA stuff, fundraising and all sorts of things, we were always helping out so I felt that I gave a lot back but I wanted to as I really valued how they were looking after and educating Archie (Paula).

Archie speaks with fondness of his kind, year 4 teacher:

The teacher was just really nice, I got to play with Lego, and go on computers on a Friday afternoon. Also, I don't know why she did this, it was really kind, I was having a bad morning I think when I first came into school, and I was literally on the computer all day. She just let me, and I was on the computer all day. She knew that I was having a bad morning and she just let me stay on the computer. She did not ever make me turn it off, I just

turned it off when I realised it was home time. She understood that I needed that time and that space. It was just a really good year in year four (Archie).

This positive experience continued into his next school even though the size of the school was double the size.

The Middle Years

The transition to this school was excellent. He is still at this school. What made the transition so good was the excellent communication and handover between schools. In addition the schools organised a members of staff, the Emotional Health Support Worker Tom, to bridge both schools. This enabled Archie to build a strong relationship with him and he felt as though he knew someone who he could turn to at his new school. The family was impressed with the amount of time that had been invested in planning this transition for Archie.

There were lots and lots of work on behalf of the First School over to the middle school. Straight from the beginning Archie had a very empathetic teacher who challenged him but also appreciated that if there was something a little bit quirky he would allow it or facilitate it. He also had a one to one who was also really empathetic. So right from day one he walked to school independently which was a big step; that was fantastic, we have never looked back. He just went from strength to strength to strength (Paula).

However, Archie is now in his second year at this school and it hasn't been as good a start for him as his previous year. Paula feels that he has struggled:

Not a good start at all, I was and have been a bit disappointed with that overlap. Disappointed in the sense that Archie changed very quickly from the moment that he started Year 6. Again, a little bit like what he was like in year 3, his whole demeanor changed at home. His personality became very aggressive and very violent. He entirely changed at home, unhappy, begging us not to send him to school.

I think it has been the expectation of the work and what is expected of him in in terms of the quantity and the timetable, and with the homework. Also at the start there hasn't been as much of a connection between him and the

teacher. Well that's fair enough, you are always going to get teachers that you don't connect or that aren't as empathetic. That's life but it has been very, very difficult. We had to have a meeting to try to sort it out.

We have had to have the Emotional Health Support Worker, Tom, back on board because that that's the link. That's made a big difference (Paula).

Archie talks about the wobbly start to year 6 but then talks about how it has improved.

I did homework but now I only do math-athletics and spellings because there was loads of homework to do; too much. They changed it because it was getting stressful and depressing at home for me, so it was shaky at the start of year 6 but now it's really good. My teacher is really good. In terms of my autism and Asperger's it's really good. People understand it. I can do a front flip now (Archie).

Archie is still in year 6 and both mum and Archie are happy with how it is going. Archie can really only see the 'here and now'.

Paula's story then turns to the fears she has for Archie's future.

It is difficult because Archie is always in the back of mind, most parents although you don't know what is going to happen to your children in the back of your mind there is that 'somewhere' feeling that they might want to college or they might get a job or they might want to go to University and then one day they leave home and they might meet somebody and live somewhere. I don't have that at the back of my mind, I would like to and I want to. I hope for that and I strive for that but at the back of my mind I don't know if that is going to be a reality (Paula).

Let us hope it is.

Frankie's and Charlotte's Story

Frankie is delightful, polite, young man who was born following a rather traumatic birth. The labour was long and lasted for 16 hours. Frankie was oxygen starved and he had no responses, and was resuscitated and taken to the special care unit with his mother. Frankie's mum is called Charlotte.

Charlotte had noticed from a very early age that Frankie was different from his peer group. Whilst Frankie began walking at 6 months and was up and running by 9 months he still had no speech until 1½ yrs old. He was diagnosed with Autism at the age of three after staff at a nursery spotted that something was amiss. He used to charge around the place with arms flailing and screaming. He used to turn the whole place upside down as he was unable to cope with the busy, noisy environment.

Frankie has complex needs. He has a history of significant speech and language difficulties; markedly so in the area of receptive skills and expressive skills. He experiences difficulties with using language in a social situation. However, his use of spoken language has improved dramatically but he struggles with understanding of literal language eg 'pull your socks up' and does not understand verbal humour. At times he uses echoed language. Frankie also has sensory integration difficulties. He is sensitive to loud music, extreme frequencies and texture. He finds queuing; where he might be touched, difficult. Frankie also has some obsessional behaviours such as being fixated on computers, play stations etc. He becomes very distressed when routines are changed.

Frankie loves gaming and would spend hours fine tuning his skills! More recently, since turning 16, Frankie is starting to become more independent. He described going into the local town with a friend and how much he enjoyed it. He also talks about his future 18 birthday party with big plans in mind!

Early years

Following Frankie's diagnosis of autism he was removed from the mainstream nursery and placed into a specialist autism unit. It was here that Charlotte reports Frankie becoming unhappy due to him just being around others with severe autism.

Within 12 days Frankie started to copy severe autistic behaviours not previously displayed, e.g. eye gouging, head-banging etc. I asked if it was possible for him to have a little more supervised contact with ordinary children, but the unit was unable to accommodate this request. Frankie continued to regress into more severe autistic behaviours.

One of his friends had a thing about squishy eyes and of course his little friend would try to do that and he'd try to do it to Frankie. Frankie picked it up and he started doing it to him, not with any malice but it was just a sort of Squishy thing. He then started doing it at home, trying to slip his eye in, and squish his eyeball out. Scary stuff. As soon as he saw his friend climbing a wall he would copy his behaviour. He was just modelling that behaviour. At that stage, I knew he was not in the right place. They would say 'okay- he's autistic, we're not going to try and prise him out of the bubble we going to let him be; we're not going to try and mainstream him at all. It was such a tiny unit, and the two boys that were with Frankie were severely autistic, (further along the spectrum than Frankie was), one of them kept escaping even over 15-foot wire fencing. He would just run and run and run, he had no communication, and lots of sitting and rocking.

The staff were good. They tried to get Frankie to recognise his name, and they created a reward system where they gave them a little raisin and Frankie managed to spell his name. There was a little blue dot and whenever Frankie saw that blue dot he was like 'that's me!' We don't know why the blue dot worked but it did. (Charlotte).

Frankie doesn't have particularly strong memories of this provision but does remember feeling comfortable there.

The Next School

In 2003 Frankie joined a school, which had a specialised unit attached to its mainstream provision. It was a large, town primary school. Charlotte was delighted with the support and education that Frankie received whilst at this provision.

We luckily found a special needs unit at a town school run by a teacher and

her marvellous team; there were small groups, special spaces and a special allocated playground. They used visual timetables, signing, the lot! Frankie came on in leaps and bounds and started to communicate with sentences.

It was fantastic. The staff made it fantastic, they were very well trained, very experienced, and the head that set it up must've been very forward thinking. They had a lovely sensory room. It was a lovely room, and as soon as you went in there was that calming nice feeling about the place; you felt welcomed and safe (Charlotte.)

Frankie did very well at this school and mum reported that Frankie was very happy. Frankie recounts his time with fond memories and reports it being a lovely childhood memory:

I don't have any firm memories of nursery but I do remember being at first school when we used to go on bikes and go around in laps and I really enjoyed that. I was happy at that school because it had really good teachers so they would always understand if you were struggling with things. There was a great playground and there was also a field to chill out on. They understood me (Frankie).

Troubled Times

The next school environment for Frankie proved to be unsuccessful; it was a rather torrid time for both mum and son. Charlotte describes the next provision with raw emotion.

We did not have a good experience at the next school because there was lack of knowledge, and lack of facilities. I think the staff, although they said they were trained, only had a rudimentary idea of what it was about and did not take it seriously. If anyone had special needs I'd say do not go to this school because they cannot cope. Some dreadful things went on, for example we got the statement and we were pleased about that but you had then got to force the school to do what the statement says and they just did not do it. He was meant to have one to one, have somebody with him at all times due to both his autism and his illness but I used to pop into the school and more often than not there was nobody with him. And they used his LSA as a spare member of staff. I said to the SENCO 'you know where that member of staff is and you know he's not with Frankie!' I told the headmaster 'this is the third time that this has happened do you want me to call my solicitor?'

You fight like hell to get the statement and then you have to actually get the

school to follow that statement. All this rubbish about inclusion is bollocks basically. Some of the pupils were transferred to a specialist school. I think they are excluded to the max, its disability discrimination, they're not allowed to be in their own community. It's so desperately unfair, why should the children be shipped off to a different school? If you haven't got facilities for genetically unlucky children then you are excluding those children. Not enough money was invested in this school.

It was a nightmare from start to finish. There was no special needs unit or expertise, like I said the school regularly flouted the conditions of his Statement. I had ferocious yearly battles with County always ending up at tribunal to get Individual Learning Plans (IEP's), Speech and Language, Occupational Therapy, etc., and then have continual ferocious battles with the school to get them to do what was on the Statement. It was dreadful years. I hated them and they hated me and Frankie even more.

I was in and out like a yoyo screaming at the Headteacher about the way my son's autism was handled (Charlotte).

Frankie told me that when he went to this school things started to get harder because some of my friends from his previous school went to other schools.

I started finding new friends and that took a bit of a while, but eventually I got used to it and just learned to cope. I learnt to cope by doing what the teacher said; just doing what I had to do. Things got a bit more stressful with the work we had to do there, but I managed to get through it (Frankie)

Frankie could not remember much about this school but he was quite clear that he did not enjoy it as much as his previous experience where he encountered a feeling of being comfortable and accepted. He knew that he had not felt that at this school.

Happier Times

Frankie then transferred to another mainstream school. He is still there now. This has proved to be much more successful.

He took some time to settle in and for everybody to get used to each other, but he has gained in confidence and he now enjoys his lessons and feels like he is a proper person who has a place in the pattern of life. He still has a lot of time off for illness, but he seems to be managing even so. Thank goodness for the S.E.N team, nurture base, and a proper sickbay with a nurse! Not

just saying that, it makes the world of difference for Frankie, as there is no other school nearby for him to go to. I think the staff at the school have been marvellous.

He now has a friend called Tim and Tim is very good with Frankie; they balance each other out. At the school the staff are very kind to him. I think it's mainly the staff that make it work because at the other school they were not particularly kind to him. He was viewed as a problem. Do you know at that other school one staff member said to another child who had autism, 'If you mention Dr Who one more time I will tell you to shut up for the rest of the day.' You cannot turn around to an autistic child and tell them to shut up!

I think at this school Frankie has had a much better relationship with the teachers and his LSAs are very friendly as well. I am happy with the support, and he has enjoyed it because he's treated more like a grown up. The staff talk to him on a level that he is happy with and they have a laugh and a joke which he understands (Charlotte)

Frankie enjoyed the move to his new school and talked with enthusiasm about his new found independence and his love of school.

I am getting more independent now doing my own stuff and I went to town with Tim. This school has taught me that I don't just have to rely on other people to get things done. Now I can just go up to Mum and say 'I'm going to go out now' and she'll say 'that's fine'. It has been a bit stressful because of the change of staff and things like that but it is just one of those things that you cope with and I'm getting used to it now- because I am more independent.

I have really good support at school. There have been some very good moments with my LSA, it's very entertaining. The support makes it great because you can relate to them as you get more acquainted with them and get things sorted out quicker rather than getting someone you don't really like or know helping you.. On a scale of one to 10 I would rate the school an 8.5 because it's been great with all the courses I like doing. I love Asdan and the teacher is great.

What makes school good for me and with my autism is that when you come to decisions in life, talk about it. I like people that understand me and having great help from teachers that help you through the lessons themselves. It's good to feel like an individual and you don't have to worry about what others think. I used to worry about that in my other school but that was just part of growing up (Frankie).

Mum talks about Frankie's future and her worry that he still exhibits risky behaviours.

I know that he still has risky behaviour; and I know I will be dealing with that for a long time. For example in London he just switched off to deal with all the noise and commotion of the place. If I was not with him he would have just wandered off and got lost (Charlotte.)

What was apparent was the optimism for the future that came from both Charlotte and Frankie. Frankie has clear goals and ambitions. Charlotte has the drive to help him get to there.

John's and Tracey's Story

John is a delightful young man who is in the last year of schooling. The nearest town is 15 miles away. His mum, Tracey, gave birth to him in a cottage hospital. John was 2 days early. It was a natural, uneventful, easy birth. From a very early age Tracey knew that she had a son with a difference, *'call it mother instincts'*. John spoke a little bit later than others and when he did speak Tracey described it to be in true *'John style'; long and amazing, articulate sentences from the moment he started to speak.'*

John is very polite and well spoken; he is extremely articulate. He is high functioning and is very intelligent. John was diagnosed as being on the Autistic Spectrum in 2008 at the Combined Disorder Clinic; he was 9. Throughout his schooling there have been a considerable amount of input from the Educational Psychologist, Children and Mental Health Service (CAMHS) and the advisory teacher for autism.

When John and mum heard that I was doing my doctorate about inclusion they both felt very strongly that they wanted to take part, *'it is important that others hear our story'*. The following is their experience.

Early Schooling

Before moving to the rural countryside, John's family used to live in a town. John attended the local primary school. The first memorable, critical incident that happened at school, which Tracey can remember, was when John joined the reception class.

John went to a primary school for a term; it was mainly negative. To sum it all up at this primary school teacher the reception teacher came out onto the playground one afternoon and said I have been a teacher for 30 years and I just cannot quite fit John into a box. She just could not work it out. John was about 4 or 5. He had lots of social issues. He was unable to read people; he got terribly frustrated and had lots of frustrated episodes. He had difficulties with social relationships. John was quiet and a loner and was unable to do 'small talk'. He struggled to understand multiple instructions and some people started to call him, 'thick'. I felt teachers did not understand him and accused him of being difficult. This had happened right through nursery and no one understood that it might be autism. At the time I did not know anything about autism and I had no idea that I could possibly have a child that was actually on the spectrum. What got him through was his English; he was so creative and so good at English right from the start of school. He loved books. At this stage I knew something was different but no one ever, ever suggested that I should have a diagnosis or that he would need to see someone. It's interesting I recently sent an e-mail to someone saying that there needs to be more awareness of autism within mainstream schools. No, actually there is more awareness but absolutely no more understanding or support of autism; this hasn't improved in the last 10 years. (Tracey, parent).

John's first recollection of the same school was having an overwhelming feeling of unhappiness and frustration.

I was chronically bullied by my best friend and felt that I was not understood. I remember there being a thunderstorm and no one could leave the school. I panicked and the teacher shouted at me. I blossomed red and felt closed in by everyone. I did not do anything for one hour. I remember crying a lot, pulling chairs over, tipping tables and curling up on the floor like a baby (John).

John could not remember anything else about this time. He just remembered that he did not like this school. Tracey echoed those feelings. The family then moved to a small, rural village. He attended his next school for one year.

The Memorable Year

John struggles with change. However, when he changed to this small, rural, village primary school both mum and John speak about it with fondness. It was a memorable year.

This school was different. I went in to see the headmaster at this school and it was then that he was the person that said to me, 'Tracey maybe he might be on the spectrum' and it was almost a relief from that moment onwards we got a referral to the hospital and within three months we had a diagnosis. It was speeded up through the doctor. It was like a massive relief (Tracey).

Tracey speaks highly of this school and mentions the kindness of the head teacher and the fact that he seemed to know what he was talking about. She was delighted that finally someone understood John and understood what she had been going through. She had previously been fighting for a diagnosis but no one was listening: it was only when the Headteacher got behind Tracey that the referral process was sped up leading to a diagnosis. She described this school like 'a family'.

John talks of a massive improvement when he attended this school. His eyes light up when he speaks about it. He cannot remember any events but can remember having friends. He kept saying how important friends are to him.

There was a massive improvement when I attended this school. This is because I had friends who could relate to me. We analysed each other's moods and looked out for each other. I did not feel lost. It was good (John).

John stayed at this school for one year before he had to transfer, with his friends to the next one.

A Rocky Start at the Next School

The transition from the village school to this town school proved difficult for John. The new school was in a town; it was much larger, much noisier, with lots more people.

At first Tracey describes incidents when teachers did not understand John's needs. They did not seem to understand that you could not spring something unexpectedly on him.

He then went to the other school and again because it was a time of change it was immensely difficult. John put his fist through a window. He was sent on a cycling trip unexpectedly and when he refused to go he was accused of being difficult. He did not mean to do it and it shocked him because he had been so good at school with his attitude of I'm okay, I'm fine, I'm fine, I'm fine but really he was not fine; he was in a screaming rage! John stood out as he is very sensitive (Tracey).

John also talked of finding the transition hard. This was mainly because of friendship groups and feeling misunderstood.

I was not understood by my headteacher. I bought a lot of rage and upset into things. I acted out a lot. I felt the headteacher understood the other boys better. My friendship group had dispersed and they started to hang out with new people and I started to lose friendships. I did not feel understood. A lot of my work was not understood, like my writing or drawing. I was drawing abstract things. There was a big misunderstanding of who I was. Teachers did not understand. I would sharpen my pencil over a girl's hair and start throwing rubbers at people. I felt as though I was stupid and people were shutting me out because of my frequent emotions. My vocabulary was good (John).

John also goes on to describe being bullied by children. He describes one event as he has called someone a 'poof' and did not quick understand its meaning as he had called his brother it lots of times. However, when he called this boy it, the boy went mad and starting chasing John.

He tried to stretch my spine on a table (John).

After Tracey describing the initial transition year she then speaks highly of the school.

The SEN department there was brilliant and because John is high functioning he was actually in nine top sets. This school was a good place

for John. I think this is because at this school we're not into exams GCSEs and multiple choice questions and I don't think they bring out the best in him. John cannot do multiple choice questions although he has the knowledge and does way over and beyond what is expected of him (Tracey).

John then describes the school as getting better year on year. In the second year, John formulates a new friendship group and reports working cooperatively in class. However, he still reports that whilst it was getting better still something's occur which made him sad; one incident sticks in his mind where a teacher '*just doesn't get him*' (John):

My maths teacher did not really understand my methods. So she would make me stay behind during break time and go over them with her; sacrificing extra portions of my own time just to do this. Those eyes. Her eyes glared into my soul. She almost penalised me for doing it my way. It was unheard off how I explained things differently (John).

However, in the third year of this school things get even better for John and he cannot remember any negative aspects.

I felt sophisticated and I used to borrow books from the library. The books would all close in on me so that I felt protected from distraction. It was a very strict year. I struck up a good friendship with a teacher and I would stay behind at break time and talk about books. I felt connected. It made me a stronger person (John).

John reported that his fourth year was amazing and brilliant. As he talked he became animated, he became more fluid in his speech and he oozed vitality. His eyes were alight with energy. His whole body and demeanor changed. This was the first time during his story that he transformed.

I felt on top of the world. I was in 9 top sets. I had adopted a new character. I did a lot of revision. The outcome came as a wave of excitement. It was astonishing. They understood me. They knew me. I was not stupid and I could talk a lot more with people and hang out in a lot more groups. It made me feel better inside. They understood my autism. I expressed my

autism in poetry. More people approved. Lots more people were sitting at my table asking for ideas (John).

On the whole this school, this school was a very positive experience for John. Tracey also was very pleased with this school. She mentions the importance of meeting John's new teachers 'every August'. So they could get to know each other.

He transferred to another school due to a family move.

The Large School.

John moved again to a new school. He is still there. This school is big with 1500 students on roll. It serves a large population. It is this school which has proved to be problematic for both John and mum.

You imagine going from nine top sets where you were able to grow and flourish to going into a place where it's exam driven and a school that is triple the size of the previous one. He has just got lost and drowned that's when is OCD started the week when he started the new school. What made it go terribly wrong is when teachers don't get it and it don't understand autism and when things are sprung on him even if it's a change of room or a supply teacher or an exam sprung on him or an assessment; that is disastrous for John. How I would weigh it up and this is also influenced by talking to parents that also got children with special educational needs is that it's about 70% towards the negative if you're in a mainstream environment. It's absolutely undone John. He is in a far worse state then he was four years ago and that's with all the support from the SENCO. I can spot this when John walks in the door what the days been like. He will tell me things or it will unravel or he will cry or he'll hit things. And I'm seeing his mental well-being and his emotional well-being deteriorate. I know things aren't right. So I'm on the case all the time; so you know I'm not relaxed. I'm always worried about John. Do you know what breaks my heart the most is that my very, very, very bright boy will not reach his potential; not even half. You have to go and speak to number 10 Downing Street. The teacher's hands are tied. Their hands are tied they are being told what they need to teach. Who's got time in a school of 1500 students to really seek out the individual? It's not the teacher's fault. I'm not actually being negative about the teachers it's got to come from higher up. The schools hands are

tied I realise that and is only so much they can do; the understanding needs a government level thinking actually.

When you've got a high -functioning child its worse; the system is worse. It is absolutely worse. They look so 'normal' that people's expectations are higher. They are not severe enough to be out of mainstream school yet mainstream school is absolutely not right.

I wish they had a format for high functioning autistic children where they go to school and enjoy all of those things but where it is all coursework, which they are good at because people like John are perfectionist. Having different exam formats are important because special needs doesn't equal stupid. Yet John will come away from school with one of two paper qualifications so to the outsider he will look stupid but yet he's not as we know he is high functioning and was in nine top sets in his previous school when the GCSE exam pressure was not on. The teachers haven't got time to read about or support the individual. It is an exam cattle market. In his previous school he was identified as being gifted and talented for three of his subjects. Some children on the autistic spectrum leave school and because they have this obsessive focus they can learn everything there is to know about a certain something; surely this can be harnessed in jobs. That energy can be channelled. Yet on paper they look stupid because they leave school with no qualifications, yet they're highly intelligent. There is no protection. They're not harnessing the potential. They've written off as children with special needs. What I found from my private work is when you have a child that is on the autistic spectrum and is high-functioning and struggling through this exam driven mainstream system they are made to feel stupid and the potential is not fulfilled so they end up tipping into the mental health arena. It is not just the exams, it is also the case of too many students and too few teachers who bother to read notes or are trained in understanding autism. The depression, the OCD, the psychosis; they would not be taken into those areas (I know they're more prone to it) if they were not made to feel so frustrated, worthless and made to feel caged and silly and so inadequate. Since joining this school John has had to go under Children and Mental Health Service (CAMHS) twice. He now has a serious mental health condition, which were not there before. Children like John might as well be given the papers in Japanese; they have got everything against them. They cannot estimate time, they cannot understand the questions, they cannot understand multiple-choice, and yet if it is someone like John who is high functioning then using these methods his potential never ever gets fulfilled. It is a cattle market with the numbers tags in their ears waiting to get through an exam system. And that's not the teacher's fault it's just the system and for some of those kids it just doesn't work.

Most of the time I feel like a pain. Is boring me just thinking that. I would ring at reception and before I even said my name they would say hello Mrs Jones and out of 3000 parents they could identify me; this is rather embarrassing. You're constantly, constantly on the ball. I know that some of the teachers I've encountered in my work when you mention the word disability they roll eyes. That is from support staff right up to higher levels of management (Tracey).

Tracey describes an incident where she is standing in a school reception with other parents waiting; openly the receptionist, a teacher and a member of the senior leadership team discuss what a pain one student with special needs is within earshot of everyone. Tracey looks at me in disbelief then carries on.

John has lost all his friends because it's a pecking order no one wants to be seen with the person that is not coping or is different. John is university material. He is chugging through the system underneath the radar. It's a poverty of ambition that is the overriding experience that I have had as a parent of an autistic child. I am tired because I know I can never stop fighting. People are quick to label so they feel as though they've done their bit actually where is the provision? Where is the understanding? It is not there; just because they've acknowledged that he is this or she is that, they feel that they have done their job. They have every right to achieve and be happy as any other person. It impacts on them the rest of their lives; all of their dreams. But forget those because they will not have the qualifications. But why cannot they have their dreams? When I really stop to think about it, I am very angry but impotent. It truly is heart shattering (Tracey).

Tracey speaks about this place with raw emotion. She feels an injustice about the current school exam system. Her pace of her speech speeds up as she becomes increasingly more angry and sad.

John also has found this school tough. He put it down to not being understood by teachers and peers, having a lack of friends and one teacher being particularly mean to him. However, all of his teachers that teach him reported that John presents as a very happy, totally committed young man who always gives of his best. This is at odds with what mum and John's stories tell. This is quite significant for mum as she points out that high functioning autistic students have

become quite good at masking their true feelings in order to be able to cope in our 'normal' world. John described how he felt when he first arrived.

I felt lost. It was far too big. I could not read the map. One teacher called me names such as 'you plank' I felt disgusted and furious. My closest friends started treating me like animals. I lost lots of friends because of what I was saying and doing (John).

John then jumped to talk about his current year and talked about him now having mental health issues. He talked about his CAMHS worker who is trying to help him cope better in life. The exam system has proved difficult for John. The heightened state of anxiety manifests itself in many ways but it becomes particularly traumatic for John during exam times.

Reflecting on John's experience Tracey sent me an email and wrote:

His mental spiralling was a direct result of being made to do mainstream exams with absolutely no support or being allowed a slightly different format, eg he cannot "do" multiple choice and line up booklets because of how his brain is wired - but given smother fairer format he'd get 100%. As soon as the exams finished he was instantly better and discharged. The mental issues were a direct result of a lack of understanding and support within school. The psychiatrist wrote this in his report. It's very important this is made clear please (Tracey).

John and Mum have high ambitions and dreams for the future.

John went on to achieve 10 a-c grades!!! He was predicted two!! A total lack of expectation surrounding him and he proved them all wrong. Hooray!! (Tracey).

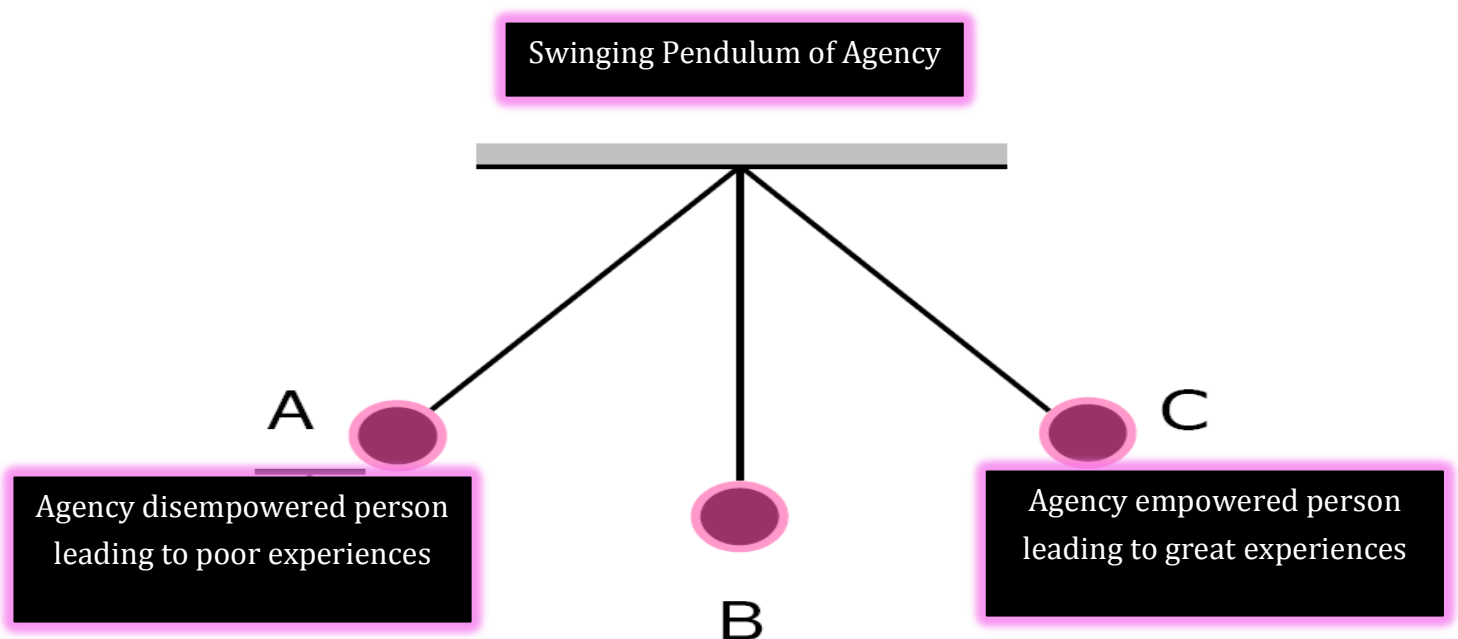
Chapter 5

Unearthing- Finding the Issues.

My findings have been presented as themes drawn from the data collected. I have included examples from all of the stories that I have gathered, including from my own personal experiences.

The inclusion experience for me and my son, the other parents and their children at a mainstream school was mixed, it was not stable and was definitely not consistent. It changed over time depending on the people that we encountered and the setting that we encountered it in. However, the changes in experiences can be attributed to one main factor: **power**. I have used elements from both a Foucauldian (1970; 1978; 1980; 1982; 1997) and Bourdieusian (1977;1983; 1984; 1990; 1991) framework to help me make sense of my findings. In particular I have used their work on capital and power in relation to **agency** and how much agency one possess in order to influence decisions: parental influence, child influence and professional influence. As the stories clearly showed the amount of agency that one possessed affected the experience the storytellers encountered. It also affected the values and attitudes that society and individuals held. In its simplicity, the more agency the storyteller owned the greater the experience they had; if agency was absent the experience was poor:

fig 4 My Swinging Pendulum of Agency demonstrates the experiences:



My aim was to listen to people’s accounts of their experience of inclusion in a mainstream school. My aim was to formulate ideas with respect to power and agency, underpinned by Bourdieu’s notion of Capital (1977; 1983; 1984; 1990; 1991). Human ‘agency’ in my terms refers to the capacity of individuals to act independently and to make their own choices; this is very dependent on the amount of capital one possesses as the capital affects the power that it can generate: please see appendix 6.

Page 45 shows my ‘theory- building model’ demonstrating the unique methodology used to gain insight into the inclusion culture.

After allowing each story to be read as stand-alone pieces of work, I then scrutinised each individual stories for positive and negative experiences e.g.

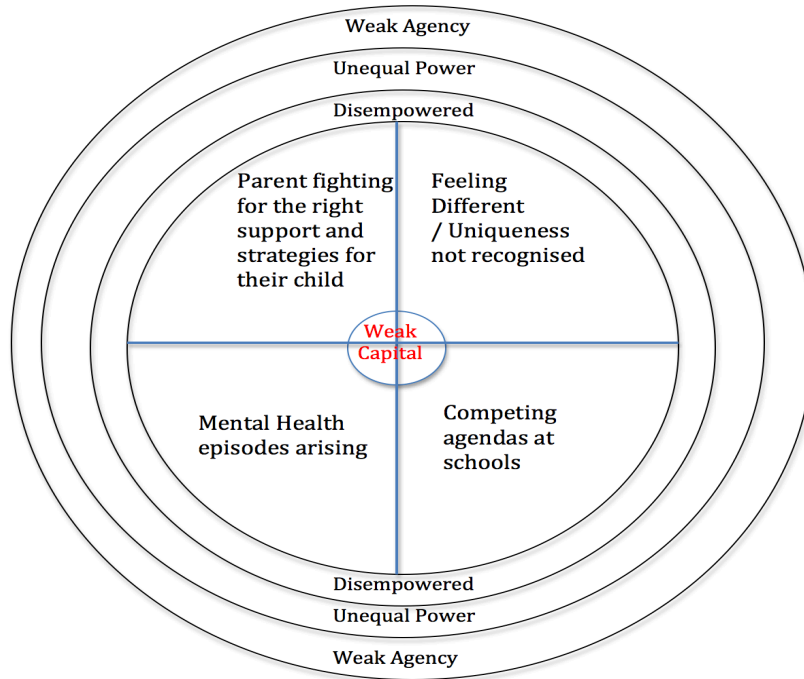
Positive Experiences	My Initial Analysis
<i>There was a massive improvement when I attended this school. This is because I had friends who could relate to me.</i>	Feeling as though he belongs and is part of a peer group. Differences recognised.

Taken from appendix 4 from John’s story.

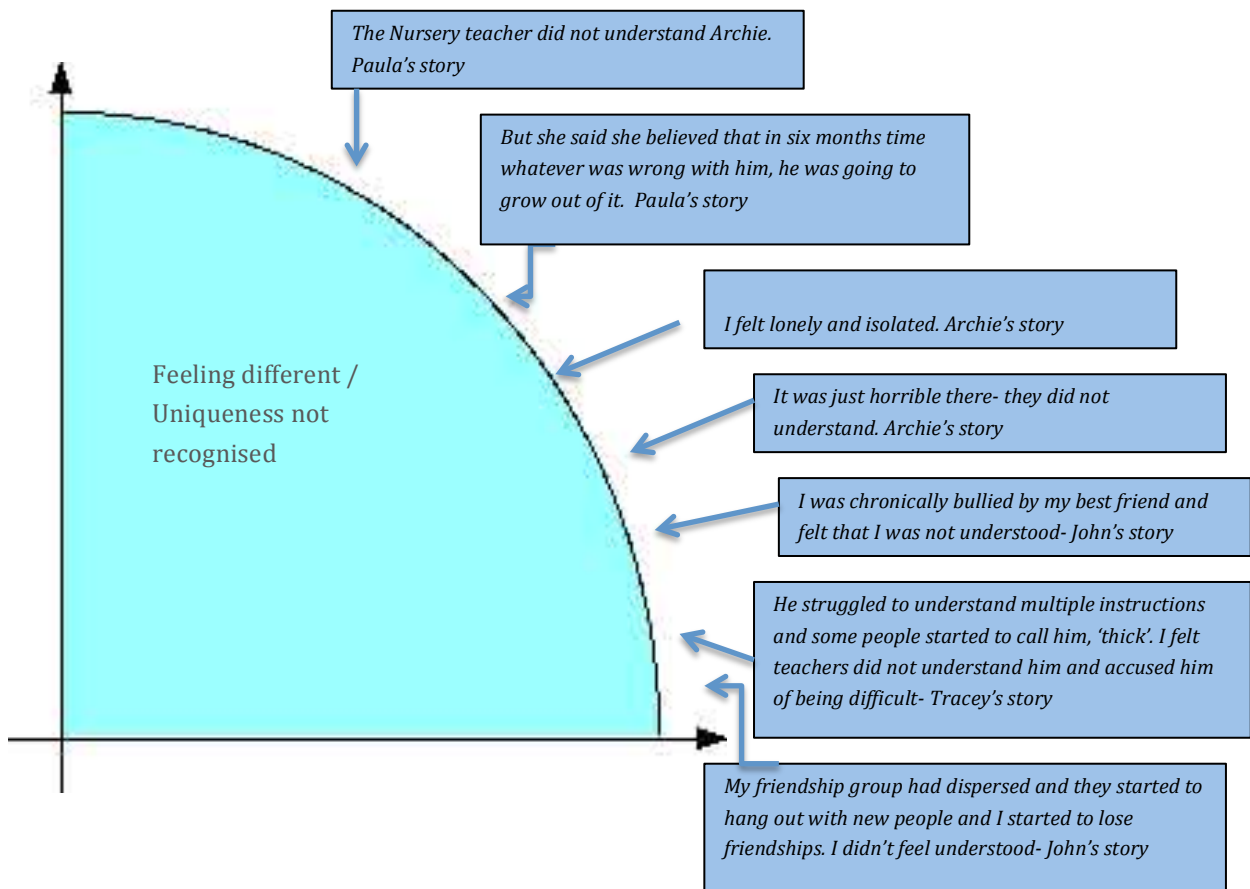
I examined each case in detail: then I drew rich, interconnected information from each singular story to get insights across the stories told, spotting similarities and differences between the case studies (Yin, 2003), What I found could be separated into four main areas:

- 1) Parents fighting for support and strategies
- 2) Feelings of difference
- 3) Relevance of Mental Health episodes.
- 4) Competing agendas at school.

I then used my model from appendix 5 to connect these themes to capital, power and agency. For example, taking the quadrant of 'feeling different/ uniqueness not being recognised' from my model below, (appendix 5)



Put all of the negative together e.g.



This demonstrated that the negative experiences related to 'difference' had an effect on how the children felt about themselves: lonely, isolated, feeling 'thick'. This affected their capital. I would suggest that their capital was potentially reduced, as their difference measured against others was not valued at that moment in time, during that encounter. It made them feel disempowered and clearly showed the uneven distribution of power. This potentially could result in the children having a weakened agency; weakening their ability to make choices about their lives and to act independently.

The other negative experiences that fell into the other three quadrants: mental health, competing agendas and parent fighting for support and strategies also showed the link between the negative experiences and how this weakened capital, power and agency. On the flip side when the experience was positive the capital was strengthened, the power was greater and the agency enhanced please see appendix 6.

Agency and SEN linguistics.

How much agency we possess can be attributed to how much capital we have to trade with (Bourdieu, 1997). This was discussed in detail earlier. However, underpinning all four themes was one main factor: linguistics. The dominant influence surrounding SEN in mainstream schools I believe can be attributed to the linguistic component which can be seen in Bourdieu's model. This, I feel, is the central theme of my findings. It determines how much overall capital one has, as it is clear that language plays a key role in defining one's agency.

Language and power are intertwined:

Equal power relations can result and be the result of symbolic violence-power and domination (Bourdieu, 1991:170).

Language is formidable. It is not a conduit merely carrying information, but instead it shapes everything. Language can be seen as social activities, as a form of cultural resource and practices; people do things with words, (Schieffelin, 1990). There are no neutral words (Ahearn, 2001). Language twists and turns and shapes our very 'being',

The subject is inscribed in language. It is a function of language that creates the systems and the rules of language and the systems of difference (Derrida, 1995:116).

People are defined by a product of partial, multiple and unstable linguistic systems. It affects values, attitudes, social actions and structures at a macro and micro level. My findings show that language, as power, creates inconsistencies and can throw a person into turmoil, directly affecting their agency, 'The chaos of values and beliefs of knowledge and power' (Kurzweil, 1975:45).

We are constructed as subjects by language, as Foucault puts it,

The individual with its identity is a product of the relation of power exercised over bodies, movements, desires and forces (1980:73–74).

My findings show that language has had an impact in three ways on the amount of capital the storytellers possessed and consequently their agency:

- 1) Firstly, the language that was used and interpreted at a localised and national level
- 2) Secondly, the linguistic capital of those individuals with SEN
- 3) Thirdly, the significant of language interactions between people.

As language challenges identities it means that it is necessary to look at linguistics to change the SEN inclusion experience for those with SEN in a mainstream setting.

If language is indeed the place where identities are built, maintained and challenged, then this also means that language is the crucible of change, both personal and social (Burr, 1995:43).

Language that is used and interpreted at a localised and national level

Language and its meaning is not fixed and it is constantly changing. The power associated with language is significant. It constructs realities. It constructs agency.

Language helps form the limits of our reality. It is our means of ordering, classifying and manipulating the world. It is through language that we become members of the human community; that the world becomes comprehensible and meaningful, we bring into existence the world in which we live (Spender 1990:3).

Language and human existence are co-dependent. At each mainstream school, each teacher, each encounter that the stories talked about had interpreted SEN in different ways, resulting in different experiences. How each storyteller felt as a human varied throughout, from anger to frustration, to joy to elation; to powerless to powerful, (Gergen, 1999). Language conveys subtleties of meaning, power relations and hidden subtext or agendas. Language cannot be seen as trivial instead it needs to be viewed as significant. Language can include, exclude, stigmatise, alienate, marginalise, depersonalise and infantilise. Language can maintain and promote inequalities; it can lead to discrimination and oppression. Language is complex and you cannot simply change words such as seen in my previous chapter in the Warnock Report, 1978 and Education Act, 1981 and more recently in the Equality Act 2010 and Children and Family Act, 2014 and consider that to be a momentous shift for SEN. I hitherto discussed the negative connotations surrounding SEN terminology and the legislation and how it was used to compensate for inequalities. Legislation, and the SEN terms we use, codify what it means to be disabled and by default promote a discourse of 'ableism'. This recreates what society comes to understand about disability and need. This is further complicated by the localised interpretations. Social difference is defined and redefined by localised criteria. We are linguistic constructions. This affects how much agency we have. The stories told clearly demonstrated the unstableness, the different values, and different interpretations attached to individuals' SEN in the different settings. Each journey was particularly rocky, eventful and all encountered immense highs and

immense lows, as shown on the diagram of the swinging pendulum of agency. Every story told of negative experiences surrounding understandings of difference at a local level.

Tracey tells of the lack of understanding:

He had lots of social issues. He was unable to read people; he got terribly frustrated and had lots of frustrated episodes. He had difficulties with social relationships. John was quiet and a loner and was unable to do 'small talk'. He struggled to understand instructions and some people started to call him, 'thick'. I felt teachers did not understand him and accused him of being difficult'

I recently sent an e-mail to someone saying that there needs to be more awareness of autism within mainstream schools. No, actually there is more awareness but absolutely no more understanding or support of autism (Tracey).

At times John felt completely misunderstood:

I felt that I was not understood. I remember there being a thunderstorm and no one could leave the school. I panicked and the teacher shouted at me. I blossomed red and felt closed in by everyone.'

I did not feel understood. A lot of my work was not understood, like my writing or drawing. I was drawing abstract things. There was a big misunderstanding of who I was (John).

Paula speaks of a year where autism traits that Archie was displaying were misinterpreted and seen as behaviour issues.

There was one year that did not work that well and I think that it was fair to say that that year the teacher really was not interested in Archie and was not that empathetic and really regarded him as a bit of a pain and a nuisance rather than properly accepting that he needed something a little bit out of the ordinary and that was not a successful year. That was just about managed (Paula).

Charlotte speaks in more forceful tones borne out of complete frustration:

I felt that the school was completely unable to grasp the seriousness of the condition, I was in and out like a yoyo screaming at the Headteacher about the way my son's autism was handled (Charlotte).

Do you know at that other school one staff member said to another child who had autism, 'If you mention Dr Who one more time I will tell you to shut up for the rest of the day (Charlotte).

Ian speaks of four years at one school with complete indignation:

Fuck all went well; nothing went well there. The teachers were bossy and strict. She was impatient with people that had disabilities like me. I hated it. It was really bad (Ian).

Lisa echoes Ian's sentiments.

They had no concept that you cannot make an autistic person come into your world- you have to try and understand their world. We're the ones that are all sitting here quite happy because we fit together quite nicely. It's Ian that doesn't fit in and they failed completely to grasp the concept of that. She treated his behaviour as bad behaviour. She was impatient and lacked empathy. They even made Ian stand out in the rain (Lisa).

The current SEN categories are surrounded in criticism for using labels that devalue and that are discriminatory (Solity, 1991) and express a language of prejudice (Corbett, 1996). Words such as 'difficulty', 'need', 'disorder', 'impairment' conjure up deficient character traits. For example, Nick is hearing impaired, Ian has Autism Spectrum Disorder (ASD); already this is painting a picture for you as the reader. Already you have images conjured up in your mind. You also have a set of values and attitudes towards these SEN terms. This maybe in your unconsciousness, as I previously described using Foucault's interpretation of the 'unthinking' (Foucault, 1997), but it is there. Meanings that are attached to linguistics are powerful. Each word said by a person holds certain values and creates certain actions or responses. The trouble is these values are not the same for each person. This is compounded by SEN being poorly defined and vague and leading to different definitions, values and interpretations depending on whom is defining it (Norwich, 2103); this variance is unacceptable. It is this variance that needs to be addressed. As Cole and Hodge

(2009) consider the SEN terms exclude pupils psychologically and socially and it cannot possibly be seen as neutral or benign. I completely agree. As it is these variances in values and attitudes that have shaped the experiences that the parents, children and young adults in my study encountered:

I particularly remember an occasion when the nursery manager called me in to tell me that yes she did think his behaviour was different and there was something different about that. But she said she believed that in six months time whatever was wrong with him, he was going to grow out of (Paula).

What made it go terribly wrong is when teachers don't get it and don't understand autism and when things are sprung on him even if it's a change of room or a supply teacher or an exam sprung on him or an assessment; that is disastrous for John (Tracey).

A deeper understanding of linguistics is necessary and how linguistics is played out in 'lived experiences'. An increased sensitivity to linguistics is absolutely necessary to ensure social values and attitudes do not devalue the disabled body. As Shilling remarks, 'that there are substantial inequalities in a symbolic value accorded to particular body forms' (2004:477). Currently, my findings would echo Oliver's work, 1996, that our mainstream system is too dependent on subjective, localised interpretations of linguistics surrounding SEN. Resulting in a varied and mixed inclusion picture.

The majority of British schools, colleges and universities remain ill-prepared to accommodate disabled student within a mainstream setting (Oliver 1996:64).

The linguistic properties of SEN are a movable and changeable phenomenon. Drawing and continual redrawing of boundaries and constructing points of demarcation, in turn are used as indices to map individuals in the mainstream environment. The making of 'difference' in schools is continually being redefined and remapped. This was very evident in everybody's stories, where every year

they encountered a different response to SEN. Foucault's, 1970, work analysed those on the margins who were responsible for the redefinitions. This resonated with each story. It was not the huge, major structural educational changes that had an impact on each parent and child but the subtler, unnoticed changes made by individuals that were significant:

Modification and shifting of cultural interest, a redistribution of opinions and judgements, wrinkles traced for the first time in the enlightened face of knowledge (Foucault, 1970:258).

It was how those small wrinkles gave rise to small ideas and practices that were taken up by individuals in different settings and in different localities that impacted on each storyteller. All underpinned by individual's linguistic understandings.

If individuals and society have a better understanding of the sensitivities and the significance surrounding language the experience for those with SEN could be enhanced. The experiences could then start to stabilise, people would start to be more innovative and creative with how they respond to differences; power would then start to be more evenly distributed. As my research shows when people have a good linguistic understanding, practice is shaped for the better leading to greater agency for both parent and child.

Frankie tells of the importance of being an individual and being understood.

What makes school good for me and with my autism is that when you come to decisions in life, talk about it. I like people that understand me and having great help from teachers that help you through the lessons themselves. It's good to feel like an individual and you don't have to worry about what others think. I used to worry about that in my other school (Frankie).

Lisa articulates the importance of understanding autism and the need for a flexible, individual approach.

They completely understood. There were times when Ian would go to school and have a complete and I mean complete rage to the point where you had to hold him because you were afraid that he would injure himself.

The Head teacher would sometimes just sit on the stairs with Ian to help him calm down (Lisa).

So not all forms of linguistic understanding of difference are translated into oppression or anti inclusive domination (Williams, 1992). There are many examples from the storytellers that delight in recalling times when life was just great. If one is more sensitive to linguistic understandings then positive experiences result as the individuals feels more in control and powerful and have more agency. Munro's work highlights the difference responses to SEN that can occur:

Difference might be said to enjoy mixed fortunes. Sometimes difference is in vogue and it is welcomed and may be referred to positively, on other occasions it is viewed as something more shadowy even malevolent with any difference being treated as deviant (Munro, 1997:14).

Responses are not confined to just schools but society as a whole. The encounters with other societal members had a lasting and a memorable impact on the storytellers. Understanding the sensitivities and significance of the linguistics surrounding SEN should be everybody's responsibility. It is the social response to the disabled person that disables, rather than the disability itself. We are not born with differences as the point of origin but rather constructed; 'by dispersion, disparity and difference by the play of domination' (Smart, 1983:59) so we are incoherent subjects; subjects that are subject to change.

Here are a few shadowy moments:

Nick looked back at awkward times when a well-meaning vicar made him feel humiliated.

Once a vicar was delivering the assembly, and as I was sitting down with the rest of school, the vicar spoke into the microphone, "Hello, can you hear me?" Everyone attending assembly had heard, started sniggering and I died of embarrassment (Nick).

Lisa talks about the lack of understanding GPs had when they were trying to get a diagnosis for Ian.

The GPs perhaps were not as experienced as they should've been on the subject of autism as there were too many boxes they wanted to tick, and because Ian held a certain level of eye contact they initially sent us away. And as I said, if there is a spectrum then children are on it at different levels, therefore you were not going to display all the same things. I actually said to the doctor, you don't have to have spots to have meningitis (Lisa).

At a church on Christmas Eve I encountered an unpleasant experience. Nick was wearing two hearing aids. He had no language at this time.

One lasting memory is on Christmas Eve. We had taken the triplets to a church service. Whilst we were there Nick started communicating in the way that only he could - by screaming. Several of the congregation turned round and tutted; culminating in one asking us to control our child (me).

A need to have a more coherent and consistent approach to linguistics surrounding SEN and how values and attitudes are shaped is necessary. There are just too many examples from the research that show negative, fluctuating experiences.

Individuals are a constituted effect of different linguistic discourses and knowledge regimes all affecting the power one holds.

Discourse can be both an instrument and an effect of power but also a hindrance, a stumbling block, the point of resistance and a starting point of an opposing strategy. Discourse transmits power and produces power; reinforces it, also undermines and exposes it, renders it fragile and makes it impossible to thwart it (Foucault, 1978: 100-101).

So particular systems of knowledge mean certain human acts and practices are seen as problematic, just like Nick screaming in the church, and are aligned to power and how subjects are positioned (Foucault, 1997). Each storyteller has been positioned as a result of his or her interactions with external forces. It shows that during good times they can exert power and have autonomy as an agent and during times of trouble it shows the absence of agency, as they were unable to resist the forces of power. As each individual relationship with different people and different contexts constitute systems of power in which

storytellers find that they are enmeshed. Using Foucault's (1999) ontological domain of 'truth' shows how certain discourses emerge by saying what is knowledgeable and valuable at that given time. These 'truths' situate people. SEN does not reside outside these multiple discourses, instead it is submerged into these discourses due to the articulated truths spoken and acted at the time. These truths can either resonate and sit comfortably with the person encountering them or be a 'bloody nightmare' as Charlotte pointed out.

The linguistic capital of those individuals with SEN

If your 'body' does not resonate with the 'truths' being told then your agency is reduced as you have less linguistic capital to trade with, creating less ability to act independently and to make choices, (Bourdieu, 1977; 1983; 1984; 1990; 1991). The last point where I raised the uncomfortable experience that we as a family had experienced one Christmas Eve, shows the importance of linguistic capital an individual possesses in a dominant, oral, language rich society. We know that management of self is critical from your accent, to your deportment, to your address, to your body movements and to your linguistic register. The linguistic capital that one possesses can maintain and promote inequalities, discrimination and oppression. Nick at the time of this event had no spoken language and his hearing aids were not powerful enough to allow him to hear sound. So he used to communicate by using a high-pitched noise that sounded like a fledgling. His linguistic register was very different. His actions were very unusual and did not fit within the 'truths' being told at the time in this particular context. It made people feel uncomfortable or irritated. All 5 children in my research have a linguistic register that would be potentially considered different than the 'norm':

Ian- He is a little obsessive about his own agenda and will happily talk at length on his chosen topic; mainly Star Wars.

Frankie- He has a history of significant speech and language difficulties; markedly so in the area of receptive skills and expressive skills. He experiences difficulties with using language in a social situation. However, his use of spoken language has improved dramatically but he

struggles with understanding of literal language e.g. 'pull your socks up' and does not understand verbal humour. At times he uses echoed language

Archie - his use of language was very advanced for his age, saying words like 'campanologist' when he was 2. He talks and reads about things that he is interested in all the time and is constantly trying to learn about them. His obsession extends to using all of his senses. Amazingly, he can identify the type of helicopter that is flying overhead by the sound of the rotor blades before he actually sees it. He is very precise and interested about anything that is technical and talks at length about this.

Nick- had no language until he was 5 and then could only say a couple of words. He speaks with a deaf intonation and is very self-conscious about it.

If we could redefine how a linguistic register is valued then the children from my research would have a better chance of acceptance and have more positive encounters. With the rise of capitalism, the hegemony of able-bodied normality has become the benchmark for judging others with impairments, 'less than human' (Oliver, 1995: 89). Nick reported being laughed at when he spoke, John being angry that people did not understand him, '*I lost lots of friends because of what I was saying and doing*' (John.), Archie standing in the middle of the road saying, 'is this dangerous?' The constant repetition of topics of interest for Archie and Ian, and Frankie getting the context of a subject incorrect due to his literal understanding: all of these contribute to lessening the linguistic capital they possessed. This potentially means that a 'disabled' body with reduced linguistic capital has less capital to trade within an education system where individuals are encouraged to be autonomous entrepreneurs of their own lives; where life is regarded as an enterprise, qualified in terms of competencies, choice, investment, human capital and geared by highly diverse needs. They have less agency. The body in this way increasingly coming to signify attitude, control and validity (Giddens, 1990) and the body has immense symbolic value. This implies that to be able to operate within this framework, you need to have a set of certain attributes. If your linguistic register compromises these attributes

you are instantly put at a disadvantage against others, (Bourdieu 1984; 1990; 1991). This further shapes disabled identities and the value of a disabled body (Bellini, 1994; Rix *et al*, 2010) and maintains and promotes negative experience, discrimination and oppression. Foucault would argue that agency is just fiction and raises the question that in fact one is never able to influence or manipulate what is happening. Power is too powerful.

Power is everywhere: not because it embraces everything, but because it comes from everywhere. And power in so far as it is permanent, repetitious, inert, and self reproducing, is simply the overall effect that emerges from all these mobilities, the concatenation that rest on each of them and seeks in turn to arrest their movement. There is no power that is exercised without a series of aims and objectives. But this does not mean that it results from the choice or decision of an individual subject (Foucault 1978:93-95).

The body is then seen as a docile target waiting to be 'done to' (Foucault 1970; 1978; 1980; 1982; 1997), the death of man. Foucault's work suggests that the power of language symbolises the constructions of disabled identities and that disabled people are an object of all consuming disciplinary power. This over bearing power constructs how SEN is perceived and can led to disempowering practices,

The power reaches into the very grain of individuals, touches their bodies and inserts into the actions and attitudes, the discourses, learning processes and everyday lives (Foucault 1980b: 39).

The notion of agency as fiction is echoed in Eribon's work, he states man has very little effect over what is happening to them; a man if they tried to influence, 'only has a sort of surface effect, a shimmer, a foam' (Eribon, 1991:161). In some case this was true for the children in my research where they felt helpless:

I found it hard to approach new people because I was afraid of what they would think of me (Nick).

I was not understood by my Headteacher. I bought a lot of rage and upset into things. I acted out a lot. I felt the Headteacher understood the other boys better (John).

I learnt to cope by doing what the teacher said; just doing what I had to do (Frankie).

It was just horrible there- they did not understand (Archie).

The emotion was raw when the children spoke of troubled times; feelings of powerlessness and lack of ability to be able to influence what was happening to them must have been a rather daunting experience. Their linguistic capital was not recognised as being valuable at these particular times.

I feel that one should not accept Foucault's and Eribon's concepts of agency as being fictional or barely relevant as if we accept these notions it has a devastating effect on how the children view themselves as people. However, I would question whether agency is completely 'free will' as it is bounded by structures. Bourdieu's framework of agency helps me to make better sense of this. He borrows and redefines habitus as a generative process that produces representations of practices by the 'structuring of structures' these practices reinforce, reconfigure or reposition the habitus, (Bourdieu, 1977:78). So, how we think is recursive. Our actions and how we view things are culturally, socially constructed by meanings and values that we attached to them. Then, in turn, our actions, perceptions and what we think then challenges culturally socially constructed meanings- reconstructing the meanings. In this way agency is not absolute 'free will' but in fact it is influenced by the cultural structures that are in place. As a habitus embodies forms and structures and fields that it is passes through. This can put constraints on individual thoughts and actions. Because of the tensions and contradictions inherent in the habitus 'actors are neither free agents nor completely socially determined products' (Williams, 1977: 113). They are a combination of both (Williams 1977; Ortner 1989).

Even though we are not completely free agents I think that it is important to recognise the place of the body in shaping practice; more value needs to be attached to the voice of the young person with SEN; more value needs to be

attached to their linguistic capital, and more value to their differences. If we do not value different linguistic registers my research show that at times the children are considered different and at odds with their peer group. It can further serve as a wedge between those with SEN and those without. Tracey recounted peer group problems:

John has lost all his friends because it's a pecking order no one wants to be seen with the person that is not coping or is different (Tracey).

Lisa echoed the difficulties that Ian faced with his peer group:

Ian was going to the classroom every morning and he would say 'morning!' and none of the kids answered him. And these were kids that he'd been to the previous school with (Lisa)

John highlighted the difficulties he encountered:

My friendship group had dispersed and they started to hang out with new people and I started to loose friendships. I did not feel understood (John).

This further reduces the capital that you have to trade with. In addition it further promotes negative encounters that the children in my study have faced.

However, it is clear that at times the children talk of feeling part of their peer group; happier times:

He is happy, he now has his own friendship group, and they are allowed to flourish in their own environment (Lisa).

I had lots of friends in that year (Archie).

He now has a friend called Tim and Tim is very good with Frankie; they balance each other out (Charlotte).

I could talk a lot more with people and hang out in a lot more groups. It made me feel better inside (John).

I have formed strong friendships with my entire year group (Nick).

All talk about these times with fondness and about how their self- identities and confidence grew during good times.

My concern for the individual child with SEN is that the mixed experiences they have had can potentially result in the children developing unpredictable outcome chains as they build their biographical account of their life; leading to reduced agency. For example, the same actions whether through speech or other can receive different responses from different people. The diverse responses in part can be attributed to the multiple discourses that surround SEN. This could potentially affect their decision-making ability as their outcome register that they have built could be potentially skewed. In addition they might make informed decisions based on little or negative experiences to draw on. They might have insufficient evidence to help them to make the correct decisions therefore reducing the linguistic capital and subsequently their agency (Evans, 2007). These mixed experiences could potentially lead to confusion. I remember as a teacher watching a child with SEN interact with their peer group asking them about Dr Who. They were all around about sixteen. Firstly, she had a positive response from one child who asked her more. The others were not so kind. They burst out laughing, mocking her obsession. I had to step in. The notion of agency as 'sub individual' the property of 'dividuals' (Daniel 1984:42; Marriot 1976: McEltinny, 1998) where someone feels torn within him or herself is particularly relevant as this could be happening within the children from my study as mixed encounters, with mixed outcomes could lead to the dilemma of how to respond to situations. I know as a mum I have frequently said to Nick, 'just make a decision'. I have heard Nick say to me many times 'mum, I do not know what to do'. This is important as an educator as we have to consider how do we facilitate children with SEN at mainstream school to discuss their singular or multiple responses that is in their head because if there is more than one response which is conflicting how do they know which one to choose? How do we give them more time to shape and verbalise their responses?

Furthermore, using Foucault's domain of ethics when describing power (Foucault 1977) shows that some of the children in my study knew that their behaviour was different than others. If you examined the actions that each individual exercised upon himself and how they assigned meaning and value to their conduct in line with the particular ideals that were relevant at that given moment in time shows on occasions that they acted differently. This code of conduct is not invented by the individual but rather the cultural models that offer the rules, opinions and advice on how to behave appropriately at that given moment, ' through which we constitute ourselves as moral agents' (Foucault, 1997C: 262). So this leads one to attach meaning and value to their own conduct:

I acted out a lot (John)

John was acutely aware of forces acting upon him; he knew that the way he was behaving was different than the way that he should. I would say that he was aware that others were managing him.

*There was a big misunderstanding of who I was. Teachers did not understand...
People were shutting me out because of my frequent emotions (John).*

Moreover, those with a reduced linguistic register can be perceived as less intelligent and less able than the speakers of the dominant 'able body' language (Bellini, 1994). This is particularly relevant for two of the children in my study as both reported feeling 'stupid' and 'thick'; when both are highly intelligent individuals; one got 10 A-C GCSEs; the other is on schedule to get 10 A or A* GCSEs. Redefining how we value different linguistic registers for individual with SEN is vital. The significance of language to the positive promotion of SEN within mainstream schools is critical if we want inclusion to work.

We need to step into the shoes of those children with SEN and find out what it is that they think and feel and give them the opportunity to 'feel' empowered. The body, the disabled body, needs to be made by and make its world. The body

needs to be seen as a living thing with flesh and blood rather than an abstract form that is a docile; that is a passive recipient of power. We need to value the body and realise it can be a practice of freedom, 'The role of this embodiment in the endless reciprocation of everyday life' (Turner, 1996:26). We need to embody the agent. As Turner states, 'it is silly to talk power without talking of freedom' (1986:64). Foucault interpretation of the absence of agency needs to be viewed with care as:

The bodies that appear in Foucault's work do not enjoy a prolonged visibility as corporal entities... It becomes extremely difficult to conceive of the body as a material component of social action (Shilling, 1993:80).

The body seen this way is made up of 'bread' and 'wine' (Hughes 2000:85) the body being devoid of material substance. We should not allow our children with SEN to be a target of power without agency, a plaything of discourse, because if we do the consequences can be devastating. This was clearly evident in my findings. The next subsection highlights what can go wrong if we choose to ignore the value of the body.

Cautionary Tale

A significant finding was the prevalence of mental health episodes in a seemingly small study. Of the five children interviewed, three had encountered mental health episodes related to their SEN, 'for every five children with special needs we know that three will have a mental health problem' (Carpenter, 2004:24). All spoke of not having friends, feeling different and feeling isolated.

At first, I found it incredibly challenging to fit in; this was a mainstream school with more than six hundred pupils with only one deaf student. Friendship groups were forming and I struggled to make friends (Nick).

My friendship group had dispersed and they started to hang out with new people and I started to lose friendships. I felt as though I was stupid and people were shutting me out because of my frequent emotions (John).

I felt lonely and isolated, I tried to play a game of football with the kids at lunch but they would not let me (Archie).

My findings are a cautionary tale. Statistically, mental health episodes have been proven to be commonplace for those with identified disabilities or need. Out of the approximately 20% who are identified as having special needs, one quarter of those will be identified as having additional mental health problems, (Emerson and Hatton, 2007; Inkelas, *et al*, 2007). This data is also reinforced by The Foundation of People with Learning Disabilities, 2005, where data suggests higher than expected rate of those with SEN encountering mental health problems and the analysis of the Office from the National Statistics, (2010) indicates that you are six times more likely to have a diagnosable psychiatric disorder than non-disabled peers.

It is important to have a sense of positive wellbeing and good mental health, it is important to feel good, to feel happiness, to feel contentment and enjoyment. It is important to function well: to function in the world and form positive relationships and social connections and be in control of your own life; and to have agency. Even if you have a good mental wellbeing you may still encounter and experience sadness, negative or painful emotions but may never encounter mental health episodes. So what has caused the mental health episodes for the three out of the five children that I interviewed? Why did they suffer and not have the resilience needed to cope? Mental health and well-being is influenced by many things e.g. age, family, poverty, self-worth, self-identity, individual attributes as well as the situations we find ourselves in. We can cope much more easily if we have resilience. However, if this resilience is eroded over time from constant setbacks that one experiences, it makes one less able to cope. The influence of power and how it shaped inclusion for these children was significant. Analysing Nick's story it read like a catalogue of life events that over time had battered his resilience, confidence and self-esteem.

*He resented them for having friends,
Not being able to speak on the phone,
Not being able to sing along with Singstar,
Not being able to talk freely,*

*Being on holiday and not being able to play and hear whilst swimming
Struggling with people who would think him 'silly' or 'thick', just
because he spoke differently
Spotting out of the corner of his eye other children nudging each other
and making eye contact when he spoke
Hello, can you hear me? The vicar shouted
People sniggering
Dying of embarrassment
Being angry about being deaf
Grieving*

From Nick's story

Nick had encountered poor mental health. He became withdrawn, and he had isolated himself from everyone. Frequently, he would cry with what he considered to be the unfairness of it. In his words he 'hated being deaf'. His self-esteem and his self-identity was at rock bottom during this time. I would attribute this to two main things, societal perception and attitudes towards and feeling different in a school where he was the only deaf person; as well as being a triplet comparing himself against his hearing siblings. Nick received counselling from Deaf Children and Adolescence Mental Health Service.

Tracey and John's story also clearly demonstrated the impact that power has on shaping discourses resulting in eroding someone's wellbeing.

The depression, the OCD, the psychosis; they would not be taken into those areas (I know they're more prone to it) if they were not made to feel so frustrated, worthless and made to feel caged and silly and so inadequate. Since joining this school John has had to go under Children and Mental Health Service (CAMHS) twice. He now has a serious mental health condition, which was not there before (Tracey).

Over time John's resilience, like Nicks, could be seen as being battered away. Here are a few snippets from his story that I would consider would knock anyone's resolve.

*I was chronically bullied by my best friend
I felt that I was not understood.
I remember a thunderstorm and no one could leave the school. I*

*panicked and the teacher shouted at me.
I pulled chairs over, tipping tables and curled up on the floor like a
baby
I refused to go on a cycling trip, I was accused of being difficult
I was not understood by my headteacher.
I brought a lot of rage and upset into things. I acted out a lot
I felt the headteacher understood the other boys better
I would sharpen my pencil over a girl's hair and start throwing rubbers
at people.
I felt as though I was stupid and people were shutting me out because
of my frequent emotions
Her eyes glared into my soul. She almost penalised me for doing it my
way.
I could not read the map.
A teacher called me names such as 'you plank'
I felt disgusted and furious.
I lost lots of friends because of what I was saying and doing.'*

From John's story.

I wonder if his resolve had been knocked, from the negative encounters he had experienced over time due to the different discourses being played by different people in different contexts? I wonder if the cumulative effect of these experiences breaks your resolve, leaving you unable to deal with tougher situations. However, it was at secondary school where due to the inappropriate exam regime John encountered a severe mental health episode. He displayed behaviours that he and his parents found very distressing.

Archie encountered a brief mental health episode when his family moved him to a new school. He felt that people did not understand him. His parents also considered the school to have poor attitudes towards difference.

His personality changed at home, he became very remote. He did not want to leave the house, he did not go out into the garden. He was very unhappy; he did not want to go to school. And previously he had never ever wanted to miss a moment at school; he begged us not to send him into school. He was very, very unhappy. It culminated one day. He was so miserable and so unhappy that when he came home from school, I think it was the day after I had received that notes in the diary and top of that lots of other difficulties,

he said that he wanted to kill himself. That was very difficult for us so he did not go back again (Paula).

I was not understood (Archie).

So out of the five children interviewed, two were being seen by CAMHS, and one spoke of wanting to kill himself whilst only eight years old. These findings were troubling.

The notion of being misunderstood and feeling different comes from our societal understanding of difference and how these views and values are translated in everyday life for those with SEN. Interpretations are changeable depending on the power and the capital you possess:

Power and the capital you possess at a given point create social differences and unequal structures (Navarro 2006:19).

However, on the flip side, my research shows that when the children and young people felt that their difference was not an issue but instead recognised and celebrated, it was clear that they flourished. At this point in time they were agent-empowered people who had linguistic capital that was valued: increasing their capacity to act and make decisions.

For example, Nick left his mainstream provision and went to a residential deaf school. After the initial settling in period, his mental health and wellbeing improved. This can be attributed to Nick embracing his deaf identity, which in turn raised his self-esteem and self-worth. He no longer felt the deaf boy in the school of 1500 but instead just felt like Nick.

Being at the school has made me develop my deaf identity, and as a result, I have formed strong friendships with my entire year group.

I feel that the school has brought out my gregarious side, which enables me to socialise more with people who share the same experiences. This has made my confidence grow and I am not shy in approaching people and talking in social situations such as parties like I was before, although I will nearly always struggle to hear them and ask them to repeat most of the

time. As a result of being more confident, I was invited by a friend to go skiing, which boosted my confidence of being deaf even more (Nick).

When John spoke of happier times at school, it was when he did not feel different and his autism was embraced:

This is because I had friends who could relate to me. We analysed each other's moods and looked out for each other. I did not feel lost. It was good. 'I felt on top of the world..... The outcome came as a wave of excitement. It was astonishing. They understood me. They knew me. I was not stupid and I could talk a lot more with people and hang out in a lot more groups. It made me feel better inside. They understood my autism. I expressed my autism in poetry. More people approved. Lots more people were sitting at my table asking for ideas (John).

After Archie's mental health episode he went back to his old school. Where he reported feeling understood by his teacher.

She understood that I needed that time and that space. It was just a really good year in year four (Archie).

He gained in confidence and he enjoyed his lessons and felt like he was a proper person who has a place in the pattern of life (Charlotte)

However, what was striking was how precarious and volatile those with SEN were. The negative encounters that they have been exposed to had weakened their resilience to be able to face future difficult times and experiences; this is true of the general population but more prevalent for those with SEN. Just listening to how Archie at the tender age of eight goes from extreme unhappiness where he wanted to kill himself to reporting extreme happiness within a space of a couple of months. Nick, going from not being able to leave the house or talk to anyone yet months later in his new environment he talked about his natural gregarious side being exposed!

SEN provision needs stabilising in mainstream schools so that the experience for those encountering it becomes reliable year on year. A need to address the inequality in power would seem prudent. Placing more positive emphasis on

differences and seeing the individuals, as *individuals* is fundamental in ensuring more optimistic experiences and an equilibrium of power. The voice of the young person with SEN needs to be heard. There is a need to increase their linguistic capital so it holds more value. There is a need to promote agency and feelings of self-worth where you can make decisions about your own life. It is troubling to think that currently we have an education system that is increasing the likelihood for an individual with SEN to encounter mental health.

The way we interact with others through language can create and construct realities and power (Foucault, 1977). As we have seen above it can have an upsetting impact on individuals with SEN. However, this is not confined just to those with SEN as the interactions and the distribution of power affects everyone. In this case the parents.

As previously mentioned, social practice is a combination of structure and agency based on interactions and power relations in social fields, (Bourdieu, 1991). The interactions are dominated by who holds the power at a given moment in time. I will now look at this aspect through the eyes of the parents and the fight and interactions that they have had as this was a reoccurring theme throughout the stories told.

The significance of language interactions between people.

Each parent talked about a struggle or a fight that they had encountered throughout their child's time at a mainstream school. Worryingly, three out of the five parents reported feeling hated, a nuisance or just unliked. This was always during times when a battle was taking place.

Charlotte stated she felt hated:

It was dreadful during those years. I hated them and they hated me and Frankie even more (Charlotte).

Tracey described feeling like a nuisance:

Most of the time I felt like a pain. It's boring me just thinking that. I would ring at reception and before I even said my name they would say hello Mrs Jones and out of 3000 parents they could identify me; this is rather embarrassing (Tracey).

I felt like a threat, uncomfortable and unliked. I think this really became apparent when at the last annual review before the emergency one for Nick, the SENCO had invited fourteen professionals to attend from various backgrounds; psychology, education, Local Authority and mental health. The school wanted to convey the message that a mainstream school could meet Nick's needs. My husband's, Nick's and my views were different. These linguistic interactions with others can redefine values, attitude and practices attached to SEN. I felt so uncomfortable and nervous during my encounter. I cannot imagine ever putting someone in the position that I found myself in.

It felt reading the stories that if you challenged or questioned you were more prone to being a target for contempt,

Insidious leniencies, petty cruelties, small acts of cunning, calculated methods, techniques that permit to the fabrication of the individual (Foucault, 1991: 308).

All of these encounters redistribute power (Foucault, 1970) and affect how someone feels or how they fit in. The battles were emotionally draining for the storytellers.

This led me to question why did we have to fight? If we won battles, why? If not, why? Again understanding the power of linguistics surrounding SEN was helpful in allowing me to understand their stories and to make sense of my findings. Each storyteller's experience was affected by how the linguistics of SEN had been interpreted and played out at a localized level. As values and attitudes and practice were changeable so were the relationships between the parents and others. This affected the power that one possessed. As Foucault explained power is not an absolute entity that you either have or have not but rather it is a property of the interactions between individuals, groups and institutions. Power

is fluid and is open to change and influence. Foucault's work can be seen as an interpretation of individual cases and their particular uniqueness at particular times, and is a feature of all social relations, 'What I am attentive to is the fact that every human relation to some degree is a power relation' (Foucault, 1988:168).

All parents interviewed told of their plight. There were times when they felt that the provision and understanding of their child's needs was just not good enough.

My husband and I realised that we needed to have a Statement of Special Educational Needs to ensure that Nick's needs were not only identified with accompanying recommended strategies for all educational professionals to follow, but that we had legal protection surrounding his provision.

When Nick was 6, we applied for a Statement of Special Educational Needs. After a gruelling fight and a lengthy appeal we eventually got it (me).

I kept on wondering why did we have to fight so hard? Why did it go to appeal? Surely, the powers that be must have realised that Nick had no language and that he was profoundly deaf? Was he not 'disabled' enough? Who had linguistically defined this? I could not believe that it took us one year from start to finish to obtain a Statement for Nick. Even to this day I reflect on this process that we encountered and wonder what would have happened if I did not have the linguistic capital to successfully navigate our way through the system. At this time I was a Principal of a Special Needs College; I knew the system like the back of my hand and I was not going to be deterred, I knew I held enough power and agency to achieve a successful outcome. Another person with less resolve and less linguistic knowledge may not have started the process, or may have given up as soon as the initial request was rejected.

The other storytellers encountered many battles. Charlotte who is very articulate and possesses a detailed knowledge of SEN described her fight with immense passion when trying to get a Statement of SEN for her son.

You fight like hell to get the statement and then you have to actually get the school to follow that statement. All this rubbish about inclusion is bollocks basically. I had ferocious yearly battles with County always ending up at tribunal (Charlotte).

She possessed the necessary linguistic capital to successfully steer her way through this process. She had agency and was able to make decisions about whether to fight or not. The fight lasted years and again I wonder how many other parents would have just given up or not even embarked on the journey in the first place? And how many would have had the linguistic power to have fought and won?

Paula and Lisa had to fight for a diagnosis for their sons. What was memorable for Lisa was the narrow view that doctors had taken with her about Ian's diagnosis of autism and for Paula she described the experience as a battle that left her feeling exhausted and poorly, resulting in time off work.

We did not have to fight for the ADHD diagnosis but we were 100% convinced- as was any other person who was medical who had met Archie was convinced - that he also had Asperger's. It was harder to get this recognition but we felt that was important for his education, for us and for him, so we pushed for that and I would say that diagnosis probably took about a year. Because we had to go through assessments, speech and language, occupational therapist, education psychologists, we had to go through the whole process. And we just had to be quite persistent (Paula).

But nevertheless, they both got what they wanted: a diagnosis. Knowing Lisa and Paula as I do, I know that both have the linguistic capital that would have helped them to achieve this, both are very articulate and SEN savvy. Both again displayed agency in controlling the decisions made.

It is a concern that a fight has to occur in the first place. If we had different values and attitudes attached to SEN linguistics then this would not be happening. We need to redistribute the power to make it more even.

What was noticeable in the parent's stories was that if they chose to battle with either the medical profession or the Local Authority, they won. However, battles at schools were not as easy to overcome. This had a dramatic effect on the mainstream experiences for the students and how inclusion was shaped.

They ignored me; he fell further and further behind. I volunteered to help in the classroom to make sure that he was doing it. We should not have to resort to that. However, the teachers did not help. You can put a sign up and say 'inclusion' anywhere, but if it is really happening it is a different kettle of fish. Anybody can put at the notice and say 'we do this (Lisa).

For Lisa this battle lasted four years. She never felt that it was completely right for her child.

They took him out of lessons, they took him out of ICT, they put him on the Wii, they set up a thing called golden club, which was meant to be some kind of reward thing, that I believe was behaviour based and not academically based... It was just foolish. It was lazy. Sometimes, in order to benefit their own schedules, it was easier to take Ian out, and have him sat alongside them colouring. The staff used it as planning and prep time (Lisa).

As revealed earlier, Ian, her son, felt the same: powerless.

Fuck all went well; nothing went well there (Ian).

Some school battles for Charlotte could not be overcome. Again, this battle lasted four years.

It was a nightmare from start to finish. There was no special needs unit or expertise, like I said the school regularly flouted the conditions of his Statement. I had ferocious yearly battles with County always ending up at tribunal to get Individual Learning Plans (ILP's), Speech and Language, Occupational Therapy, etc., and then have continual ferocious battles with the school to get them to do what was on the Statement. They were dreadful years (Charlotte).

Paula lost her battle at one of the schools Archie attended despite careful and thorough transition planning:

I felt angry that people did not want to help or were not doing anything to oversee his pastoral welfare. We did not know what to do but we took him out and we had nowhere to go for about three days (Paula).

Tracey's story covers a long three-year battle at one of the schools John attended:

How I would weigh it up and this is also influenced by talking to parents that also got children with special educational needs is that it's about 70% towards the negative if you're in a mainstream environment. It has absolutely undone John. He is in a far worse state than he was four years ago and that's with all the support from the SENCO. I can spot this when John walks in the door what the day's been like. He will tell me things or it will unravel or he will cry or he'll hit things. And I'm seeing his mental wellbeing and his emotional well-being deteriorate. I know things aren't right. So I'm on the case all the time; so you know I'm not relaxed. I'm always worried about John. Do you know what breaks my heart the most is that my very, very, very bright boy will not reach his potential; not even half (Tracey).

What is concerning is that all of these parents are not only highly articulate individuals but all have a detailed knowledge of the SEN system. Why did their SEN linguistic capital, which in my professional opinion I would consider all these parents to have in abundance, not allow them to win these school battles as they had done with the medical professionals and Local Authorities? What was happening at schools that would make it so difficult to shift and influence practice? Why were the teacher's values and attitudes attached to SEN so at odds with the parents and children? Why did the teachers seem to hold more power and have the dominant voice? And lastly, why was the voice of the parent not listened to, why was their agency reduced? In three of the stories they reported battles lasted for years: in two stories up to four years. All stories clearly indicated that when SEN is interpreted with a degree of flexibility and, recognises each of their child's particular unique need, the experience for their child is good and positive within a mainstream setting. How easy this is to achieve needs to be questioned as previously mentioned in my contextualization

chapter; 'making sense of the historical and current conversations surrounding inclusion' schools and teachers have numerous external other pressures put upon them. I would propose that it is the pressure of other agendas that at times make the teacher at a mainstream school inflexible and unwilling to listen to the parents.

Power of other agendas weakening the linguistic value of SEN further damaging the interactions between parents and relationships.

You have to go and speak to number 10 Downing Street. The teacher's hands are tied. Their hands are tied they are being told what they need to teach. Who's got time in a school of 1500 students to really seek out the individual? It's not the teacher's fault. I'm not actually being negative about the teachers it's got to come from higher up. The schools hands are tied I realise that and there is only so much they can do; the understanding needs a government level thinking actually (Tracey).

The 'power' of other agendas and the values that one attaches to SEN could be putting a strain on the teacher/ parent relationships and consequently affecting the linguistic capital a parent holds, in turn having a direct impact on inclusion for the children in my research. As more 'powerful' forces and more 'important' agendas could be driving the teacher's foci, (Mittler's 2006). And it does not matter how much someone knows the SEN system or how much SEN linguistic capital a parent holds it is not deemed important, as others in the education system hold different interpretations of SEN. This repositions SEN as being less important. In addition, an increase in marketisation of education can be seen as not supporting inclusion. As our market -led system has relied heavily on data and league tables. Giving too high a profile to SEN may not match with concerns to promote a market image based on a high level of pupil achievement (Bines, 1995). Schools can be seen as too busy trying to do well in league table resulting in many schools ignoring a more equitable, coherent and humane policy for SEN students: diluting the interpretation of inclusion (Tomlinson, 2005); resulting in oppression for many.

When you have a child that is on the autistic spectrum and is high-functioning and struggling through this exam driven mainstream system

they are made to feel stupid and the potential is not fulfilled so they end up tipping into the mental health arena.....

It is a cattle market with the numbers tags in their ears waiting to get through an exam system. And that's not the teacher's fault it's just the system and for some of those kids it just doesn't work (Tracey).

However, if educational professionals interpreted other agendas with creativity and attached more value to SEN then I believe those children and young people in my research would have a higher chance of reaching their potential. The curriculum needs to be more flexible, innovative and personal to the needs of the child. By looking at what individuals are capable of, seeking their true abilities, their hopes, their dreams and their talents, and having a holistic understanding of every single individual, they then have the potential to lead great lives, (O'Brian, 2002). Let us deepen the conversations that we have with individuals, and connect with them and stand in their shoes. Let us redefine our linguistic understanding of SEN. Let us really listen to the parents and children. The results can be truly remarkable as the stories told show:

Paula's experience:

They recognised that sometimes they might be in the middle of a lesson and if he heard a helicopter that it was okay to take him out and sit in the playground for five minutes to watch it. He was given those opportunities to go off and do something a bit different. They had an acceptance that he was just a little bit different (Paula).

Archie's experience:

Also, I don't know why she did this, it was really kind, I was having a bad morning I think when I first came into school, and I was literally on the computer all day. She just let me, and I was on the computer all day. She knew that I was having a bad morning and she just let me stay on the computer. She did not ever make me turn it off, I just turned it off when I realised it was home time (Archie).

Charlotte's experience:

We luckily found a special needs unit at a town school run by a teacher and her marvellous team; there were small groups, special spaces and a special allocated playground. They used visual timetables, signing, the lot! Frankie

came on in leaps and bounds and started to communicate with sentences (Charlotte).

Lisa's experience:

The Headteacher he was fantastic; he was very, very flexible. All staff knew that if Ian needed time out to this room, then he needed to go.....At the time Ian's diet would consist of chips and ice cream. When I told them this they just said 'yeah that's ok, of course we can do that.' They just were not judgmental. They took it as it came...The last year at the school was brilliant again the teacher was absolutely brilliant (Lisa).

John's experience:

The outcome came as a wave of excitement. It was astonishing. They understood me. They knew me. I was not stupid and I could talk a lot more with people and hang out in a lot more groups. It made me feel better inside (John).

Nick's experience:

The school has just over two hundred students, and each class usually consists of twelve pupils. This was very helpful to my needs, and communication was maintained via group interface headsets. I also received weekly speech therapy, which would improve my speech dramatically. Being at the school has made me develop my deaf identity, and as a result, I have formed strong friendships with my entire year group, which is made up of about twenty-five pupils (Nick).

Frankie's experience:

I have really good support at school. There have been some very good moments with my LSA, it's very entertaining. The support makes it great (Frankie).

The difference an innovative, creative, individualised response makes to individuals in my research has been staggering. It is clear that they feel valued during these times and have a sense of belonging. However, my research suggests that there are too many times when uniqueness is not being recognised and catered for as people have wildly different interpretations surrounding the linguistics of SEN: interpretations creating values, attitudes and practice which

is too varied and localised. I would further suggest that it does not identify the student as a self-autonomous entrepreneur who should have choice, power and necessary skills to be able to influence their chosen educational pathway and later life decisions; one's agency. The power distribution is constantly in flux and is shifting and moving every moment of every day.

Conclusion of findings

The use of Bourdieusian and Foucaultian frameworks has allowed fluidity in interpreting the realities from the storytellers. The inclusion experience for parents, and children at a mainstream school was varied. There were incredibly good times and horrible times. However, what was clear was there were too many negative experiences for both parent and child. These experiences had a detrimental affect on health. This contributed to three out of the five children having mental health episodes. In addition a parent had to take time off work due to exhaustion. Our responses in today's UK mainstream education system to SEN at a localised and national level should not be increasing the likelihood for an individual to encounter mental health. By placing more emphasis on attitudes and values and recognising the individuals, as individuals are fundamental in ensuring more positive encounters. A more detailed and sensitive approach to the linguistics surrounding SEN needs to be looked at in depth as this moulds values, attitudes and practices. The power associated with language is significant as it constructs realities: realities that are sometimes very unpleasant. The more the power can be equably distributed the higher chance we will have of stabilising the SEN system. The child and parent will then be more likely to have a positive experience at a mainstream school. We need to listen to the parents and children and empower them as agents of their own lives. To achieve this firstly, a redefinition of SEN language that is used and interpreted at a localised and national level is necessary. Secondly, a redefinition of the values attached to language used by those individuals with SEN is essential and thirdly, we need to understand the significance of language interactions between people and how this shapes inclusion and how it makes

you feel. A readdressing of power so that it is more even is necessary to give people more capital and promote a society where personal agency can flourish.

Chapter 6

The Long Road to Discovery

My research journey has been enlightening and has helped me gain a better understanding of the experiences encountered for children and parents of inclusion in mainstream schools. This was aided by the autoethnographical approach that I used as my methodology. Using autoethnography connected the stories to the cultural and social and political world; it allowed me to use reflexivity to illustrate intersections between self and structures within society (Berry and Clair, 2011). It allowed me to overlay a Foucauldian and Bourdieusian framework to better make sense of what was unfolding; how linguistic capital affected power and agency.

Through autoethnography I got a chance to tell my own story, to externalise my inner dialogue and to start to make sense of Nick's and my unique world experiences (Russel, 1998) by using a systematic reflection and a scholarly approach by seeking commonalities between my story and the other stories told. My fellow storytellers, other community members, helped me to make sense of a particular issue that had emerged within my life as a parent of a child with SEN. (Wendt and Leathers, 2009). As an autoethnographical researcher I was an 'insider' in the research setting. This gave me a privileged position: I understood what they had encountered as I had encountered my own versions. I had a child with special educational needs that had gone through a mainstream system before going to a residential school for the deaf. I had rich experiences to share and others' rich experiences to mine. I also had a personal investment in how SEN was being represented (Jago, 2002;2011).

Autoethnography healing properties have been significant for me as writing has been a cathartic process. It has allowed me to make sense of the confusion that had existed in my world. It has allowed me to work through negative feelings and uncertainty about my cultural experiences (Tamas 2011; 2012). For some of the other storytellers it too was an emotional journey but as Tracey said of the importance of turning the negative experiences into positives:

Like you, I will never stop fighting for these kids and their families. I want to use all the experiences positively and to help so many (Tracey).

I want to turn the issues into solutions by firstly, recognising the key issues and then putting forward recommendations for parents, professional and child.

To gain knowledge and the issues that were emerging I used aspects of the purist approach to autoethnography, where stories were seen as stand alone pieces of gold: individual, unique case studies giving rise to questions and emotions in their own right (Ellis & Bochner, 2006, Vickers, 2010) combined with the rigour of an analytical approach helped me make sense of what unfolded, (Andersons, 2006). The initial use of the purist approach gave the subjectivity this research needed to promote understanding and connections with others (Ellis and Bochner, 2000). It allowed the reader to search for his or her own meaning and identify issues that lie in and around the story by using their own structure of analysis before I used a more objective structural approach to analyse findings. This allowed me to make rich, interconnected information from each singular narrative to get insights across the stories told, spotting similarities and differences between them (Yin, 2003). It gave me knowledge that I did not have before I started. It gave me knowledge that has allowed me to better understand others and my experiences of inclusion in a mainstream education setting. It gave me knowledge to be able to make recommendations for fellow professionals.

What knowledge have I gained?

What an expedition Nick, the others and I had been on. However, reflecting over the process I can see ways forward that I did not have before. I can see ways forward as a parent, as a professional and ways forward for children. The journey has been eventful, long, joyful and sometimes painful but most important illuminating! (me).

It was clear that the experiences for parents and children with SEN at a mainstream school were mixed; they were not constant and were not reliable. This was clearly evident in all the stories told.

This came as no surprise as Nick's and my own experiences had been so varied and continue to be. Last week whilst Nick was away at school we sent the following text to each other; this is what they read (me):

Hey Mum, I did a listening paper in French and I didn't do as well, got a B quite disappointed as although I know it's my weakest point by far in French, it's going to hold me back from getting an A*. My reading and writing are very good, but the listening is deeply annoying me and now I am worried about doing it for A'Level as listening will hold me back (Nick)

Don't worry Nick: I know it is frustrating but all you can do is just try your best. We are sooooo proud of you. Xxxxxxxx (me)

Yeah, but I don't want to be in a position where I can't access the top grades because of one section that really depends on my listening skills. Its annoying that I am restricted by my disability. Night mum. Love you. Xxxxx (Nick)

It clearly shows, like my findings, that how much capital one possesses affects agency and power, even down to a French syllabus not being deaf friendly. Power is constantly being defined and redefined. Power and capital create social differences and unequal structures (Navarro 2006:19) and it is happening every minute of every day. It is positioning people and shaping their identities. The following are the key issues:

- 1) All stories tellers encountered feelings of being misunderstood or feeling different than the 'norm'. This can be attributed to our societal understanding of SEN as how it is interpreted affected people's perceptions and values and experiences in everyday life. Different people, in different situations at different times value and see SEN in different ways- a term I call **contextmorphical** SEN- an ever-changing metamorphosing experience depending on the situation you are in and who holds the power with the dominant voice.

- 2) A cautionary tale emerged where those children with SEN appeared to be more volatile when they encountered difficult situations or times. This I would suggest can in part be attributed to the children's resolve being knocked over time due to the negative and inconsistent encounters surrounding SEN that they have been exposed to over their life. Three out of the five children faced mental health episodes.

Even though I was shocked a selfish part of me felt relieved, as I had always felt so alone with the mental health episode that we had experienced with Nick; in my professional and social circle mental health is not often talked about. As a mum somehow you feel like a failure as though you have done something wrong and you feel helpless that you cannot make it right and that there are no quick fixes. The experience was horrid (me).

- 3) My research suggested that competing agendas within school affected the power and weight given to SEN as more 'commanding' forces and more 'important' agendas could be driving the teacher's foci, (Mittler's 2006) Schools can be seen as too busy trying to do well in league tables resulting in many schools ignoring a more equitable, coherent and humane policy for SEN students: diluting the interpretation of SEN. Giving SEN less value and importance than it deserves. Resulting in oppression for many, giving rise to negative experiences.

Language underpins all the above points because it is how language is valued and interpreted that affects the social actions and interactions between people. The power associated with languages is significant as it constructs realities. The power you hold affects the amount of agency that you have. This can be seen in three ways:

Firstly, the language that is used and interpreted at a localised and national level: including how the curriculum is shaped for those with SEN.

Secondly, the language used by those individuals with SEN as the management of self is critical; what we say and how we say it all affects the capital we have. As a 'disabled' body with reduced linguistic capital, arguably we have less capital to trade with; the body then increasingly signifies lesser attitude, control and validity (Giddens, 1990) and therefore has immense symbolic value. So if your linguistic register is devalued it reduces the capital that you have to trade with. In addition it further promotes negative encounters that you experience. This was clearly evident in my study.

Thirdly, the significance of language interactions between people affected the experience that my storytellers had encountered.

The long road to discovery; how can we make it better?

I sat in the office at UWE and one of my supervisors advised that as it was an Education Doctorate the expectations are that you make recommendations to enhance educational practice. I pondered for a bit as my mind went all over the place. Inside I was thinking but it is far too complicated to radically transform the SEN system, so I spouted forth, 'we are a life- time away from making real meaningful changes that will have a life lasting impact',I may believe it but it will never stop me from making small steps on the long road to discovery (me).

Recommendations:

My ideas are plentiful. However, for me the main changes need to be within the education profession and school environment, shaped by government policy. The following are my recommendations:

* Please note that in some outstanding schools elements of the following are already in place.

1) Professional- increased sensitivity to linguistics within the school environment and at government level.

An increased sensitivity to language at both a local and national level is absolutely necessary to ensure social values; attitudes and actions do not devalue the 'disabled' body. The making of 'difference' in schools is continually being redefined and remapped by educational professionals and policy makers. We could start this process by ensuring teachers; and other professionals have a better understanding of and are more sensitive to the language surrounding SEN and how this influences values and attitudes; and in turn how values and attitudes shape linguistics. A deeper understanding of linguistics and their impact is absolutely necessary.

A consideration of current practice and policies, I would propose, needs to occur. The following are a few examples of how we could address the linguistics surrounding SEN so we can value difference more and give it more capital:

2) Professional- removing the labels 'SEN' and 'Additional needs' that are used at mainstream schools.

A move away from using the term 'SEN' and 'additional needs' within a mainstream school would be ideal; as by having a separate group of children identified in one totality; 'SEN' it naturally creates a 'them' and 'us' situation.

As a mum I have heard my own children describe peers as being SEN or 'you know mum, the ones that go to that special room.' I have heard as a teacher children describing other children as 'those ones' who have special needs; I have heard within groups of children who do not have SEN laughing and joking with each other saying that they have special needs when they do something wrong or inappropriate; I have even heard teachers say it (me).

By stopping using these labels within a mainstream school it would go some way to help to minimise the effect of being labelled and seen as an object of difference and at worst being seen as deficient and being 'less than human'. It would redress the power and make our school environment more equitable. It is still absolutely imperative that we as professionals know what each individual needs are (one person who has autism is very different than another who has the same diagnosis) so appropriate **individual** strategies can be put into place to maximize potential. Every single child in a school environment has a unique need that needs to be recognised. Let us celebrate everyone and let us work with everyone as **individuals**.

Interestingly, as an ex Principal of an outstanding specialist school we never used the term 'SEN' or 'additional needs' when describing any child; we only ever saw children as being unique individuals with unique needs. There was no need to separate children into sub groups (me).

In order for this happen, documentation at government level would need to be revisited. Documents and Acts, such as The SEN Code of Practice (2014) and the Children and Families Act (2014) would need to be sensitively redesigned and linguistics repositioned so that schools had the confidence and framework from which practice, ideologies and values could be reshaped. Legislation and the way we codify SEN would need to be analysed to consider the impact it can cause. Terminology and words powerfully reposition society's understanding of SEN. The law as it currently stands, I would advocate, reinforces negative perceptions about disability. Powers are dominating what is disability law and subsequently are affecting and shaping the inclusion discourse in mainstream schools; differences; such as deafness and autism need to be celebrated not benchmarked against the 'able' body.

2) Professional- re-skilling all staff who work in a mainstream school.

The last school that I worked in had 195 staff. As a professional I was always aware the total staff group; including admin, premises, support, finance, etcetera, were underutilised and were not very involved with the promotion of an inclusive school. Let me propose that all staff members that work in a school environment should be expected to work, during the course of the year, with the students. Excluding the teachers, (they could benefit from a detailed programme on '*inspirational recognising uniqueness in all course*'), all other staff groups could have to hold a professional qualification of mentoring young people; including taught sessions on different needs, within a certain amount of months of them starting their job role. Their job description could be changed to reflect that part of their role would be to mentor a certain amount of students throughout any one academic year. It will also help with every single interaction that the staff member has with any child. It is not a panacea in its own right but a step in the right direction towards inclusivity and recognising everyone's unique needs and utilising our school resources. The more staff involved, I feel, could result in a more coherent approach to valuing differences. If we leave it to a select group e.g. teachers and learning support assistants we are not seeing the potential of getting all staff involved with changing the culture, attitudes and practice towards difference. We are missing an opportunity to redefine the language surrounding SEN. If we can redefine it and enhance the value that we attach to language this will ripple out into the community and start to shift values and attitudes everywhere.

3) Professional- Consider the roles of the SENCo and the LSA staff at a mainstream school.

Consider removing the role of the SENCO at mainstream schools, as I would suggest that by having just one person responsible for SEN furthers divides and separate children. In addition, it further reinforces that certain children are just seem as one person's responsibility.

A teacher once said to me, 'you look after the special needs children don't you?' (me).

This will encourage the practice of 'recognising uniqueness in all' as it then becomes everyone's responsibility: spreading the responsibility across all staff groups. Consider replacing the SENCO with **multiple** 'Recognising Uniqueness Coordinators' who are advanced practitioners in teaching and learning. They would be responsible for coordinating information, responsible for sharing good practice, and responsible for modelling inspirational teaching and learning. In this way all children's needs would be catered for: not just those who have been singled out as being different with SEN. We would then be able to eliminate the label SEN and additional needs and stop the 'them' and 'us' scenario. That is not to say that we would stop recognising needs such as deaf unique needs, autistic unique needs; it just means that we are not separating these children into another group away from the rest of the 'other' children. The rewards would be immense.

In addition, the use of the Learning Support Assistants (LSAs) team would need to be looked at in order to maximise their use. I would propose not only that they need a professional qualification in mentoring but also a mandatory course on recognising uniqueness and empowering students. This would need to be detailed rather than just information gathering afternoons that are so often seen within schools:

I remember only too frequently sharing training opportunities with the LSA team, 'I have put the leaflet up on the staff notice board, If anyone would like to go to half a day's training on autism please let me know' (me as SENCO).

It is important that each staff group is trained and skilled in working with a diverse range of individuals. At a school we know that sometimes children need 1:1 support. Therefore, it is absolutely right and proper that the person supporting is skilled for that role. Currently, LSAs are under no obligation to obtain any mandatory qualification and some have a poor understanding of difference. This should, in my ideal world, be changed.

Throughout Nick's school life, and from reading the other stories, the quality of support has been sporadic. For example; one of Nick's learning support assistants, whilst really kind, kept on getting things wrong; simple things like putting the wrong hearing aids in the wrong ears (me).

There is a need to place more value on skilled staff working with difference. The more we can spread the skills and show the value we attach to difference the better the experience for our children. This also includes teachers:

4) Professional- skilling teaching staff.

The phrase 'all teachers are special needs teachers' (Lawson and Nash, 2010: 160) needs to be reviewed and replaced with, **all** teachers should be able to teach **all** children. In order to recognise diversity that we encounter as professionals it would seem prudent to further 'up skill' all teachers. I would propose that a significant amount of the elements from the National SENCO programme should be an inherent part of the teacher training programme rather than information only privy to a select few; currently SENCOs. Whilst there are SEN elements in the initial teacher-training programme I would propose that the detail and depth is lacking for the diversity that one sees in a mainstream school. 'Uniqueness' should underpin every element of all teacher courses so we start to see it as part of our lived world rather than a separate thing we do for a defined period of time as a module and for a defined group of people. In this way we are spreading our knowledge and understanding of difference and making it part of us; in everything we do.

The National Senco Programme gave me lots of practical advice as to how to differentiate teaching and learning and recognise need. The trouble was when I went back to try to implement it in the school environment it lost its way due to the magnitude of the task. Also, I found that teachers were all at completely different starting point: some were at the starting line; some near the finish (me).

I would consider that all teacher-training courses are about or profess to be about inspirational teaching and learning by recognising uniqueness in everybody. However, I would suggest that currently these words are not translating into actions in the classroom for everybody. We need to change the values and attitudes that

surround the language of difference. Let us skill the teachers so that they have a bank of tools and strategies to use to cater for all; this needs to be viewed as the most critical thing that we as teachers, professionals need to be able to do. Every teacher needs to understand, value and be able to teach everyone regardless of his or her difference. Opportunities need to be sought and created to promote the child's voice, and their involvement in their own learning programme; increasing their empowerment. Regular updates and courses over the academic year need to be available in order to gain the most up to date knowledge that is available. A teaching culture would need to be created where an open door policy of sharing good practice and learning from others is encouraged; not in a tokenistic manner but part of the structure of the day; part of the normal pattern of school conversations. This will further help to foster and seize inspirational teaching of uniqueness. Capturing and sharing successful moments I would consider critical. Avenues available for staff to do this are necessary; but done in a carefully managed strategic way led by the leadership team of the schools. In addition a culture would need to be encouraged where teachers feel empowered to be able to ask for help and not see it as failure if they are struggling.

4) Professional- changing policy

Let us consider scrapping the compulsory SEN policy and rebrand it and replace it with 'recognising uniqueness policy' that encompasses and celebrates every student in that school community rather than singling out groups of children. This would redefine the language surrounding SEN.

5) Professional- having a creative curriculum that is flexible and innovative.

In order to recognise and value individual needs we should consider how we could be creative and flexible within our curriculum in a mainstream school. It would be exciting if it could become a flexible enterprise to meet individual needs. Differences would then be seen as a fundamental feature of an inclusive school- where everyone has a stake and belongs. The shift for a school would be significant as it would have to change from being a collective body where a monolithic system is in place to being reorganised as a collection of temporary organisational structures that meet needs of individuals at a given point in time. Schools would then cater for

everyone (Simons, 2001). This would be really exciting. In the stories they tell of times when a flexible approach had led to great experiences. This practice is already common in many specialist schools that I have had the privilege of visiting. However, the mainstream schools that I have taught in and also the information given to me from the storytellers, suggests that this practice is often lacking due to other competing agendas in the school environment. I would propose that school leadership teams need to be brave and realise that 'one size does not fit all' and that a consideration to an alternative way that needs constant vigilance and change would be necessary. I honestly believe that if they did this then children would achieve more and reach their potential. It is ironic that apparently competing agendas such as a data driven, league table school system stops or hinders the value of SEN when I believe that if we are being creative, innovative and have exceptionally high standards it naturally leads to exceptional results; which actually improves the league tables. If curriculums were flexible it would redefine our linguistic understanding of SEN and would redefine the experience for the student. In this way the curriculum and the assessment regime would be radically transformed.

6) Professional- parental voices.

This needs to be developed within mainstream school systems. Creative ways to make parents feel valued, talked with, given time, kept updated, feel empowered and kept in the loop with their child's educational experience are vital. Thought needs to be given to the power relationships and principle of effective communication to parents as equal partners, (Lamb 2009). Redefining the value we attach to parents within SEN language.

Lastly, but most importantly,

7) Professional- empowering the child. The child-empowered agent must be at the heart of all we do. Opportunities need to be created and sought to allow the child maximum involvement in their negotiated learning journey.

Final thoughts:

It would appear we are some way from creating a truly positive inclusive experience for those who have currently been identified as having SEN in a mainstream school environment: we are on a long road to discovery. The experiences the storytellers encountered were too unstable and positive experiences were too sporadic. However they did exist, clearly demonstrating that it can be done if we redefine the language surrounding SEN and give it more value. Every individual must be seen as capable, as wanting to find their true abilities and to realise their hopes, their dreams and their full potential. Having a holistic understanding of every single individual needs to occur, differences need to be recognised and celebrated by our values, attitudes and actions. Everyone deserves to have the right to lead great lives, free from oppression, discrimination and negative experiences. Let us deepen the conversations with individuals, and connect with them and stand in their shoes. The children in my research would then have a sense of belonging in their schools; parents and child would then feel valued, and respected. The term SEN would no longer be necessary.

Limitations of my study

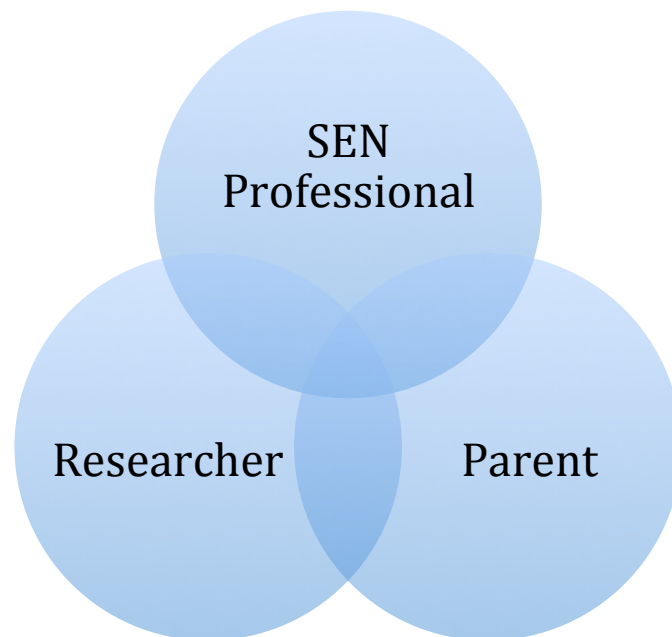
There were three main limitations that could have had a potential impact on my findings and the ability to effectively answer my research question:

- My own self-identity
- Story as 'truths' and
- Breadth of sample size.

1. My own self- identity- who was I?

Throughout this research I could be seen as having multi-identities: the researcher, the parent, the SEN professional. This may have confused or hindered the stories' told or could have actually helped with the quality that I perceived to have gained. The parents and children may have wondered whom

they were speaking to; was it to Vanessa the parent or Vanessa the researcher or Vanessa the SEN professional?



I was extra vigilant to this limitation and mindful of the complexities surrounding my identity. I kept honest and transparent throughout; I never pretended to be just one of those identities; instead I actively promoted my triple role and how they were interwoven with each other; I promoted their co-existence by sharing my roles with the storytellers. The importance of my positionality was critical in ensuring rich narratives were gained.

2. Stories as 'truths'

Whilst searching for rich personalised stories I potentially was in danger of sacrificing the truth. Another potential limitation was how did I know what was being told was the truth? As each story told possibly had changed over time and had been constructed and shaped through interactions with every experience, every encounter, every environment, including the interaction with me

(Silverman, 2000). I considered seeking the 'actual truth' was less important than the subjective reality that the child and parent shared. As truth, arguably, can only ever be seen through the eyes of the individual (Creswell, 2009). The richness came from the realities that the storytellers represented. They shared evocative, subjective realities steeped in emotion that had a significant impact on their lives. It gave me real, meaningful insight into the culture surrounding inclusion in mainstream schools. In addition, the realities could be seen as being validated by asking both the child and parent about the same experience.

- **3. Breadth of sample size**

It would have been helpful to gain stories from the professionals such as teachers, psychologists, autism specialists, and CAMHs representatives to gain a valuable insight into inclusion in mainstream school through their eyes. This, I believe, would have added further value to my research findings. The lack of their input could be potentially seen as a limitation for two main reasons: misrepresentation by the parent or child (Megford, 2006) and secondly, ignoring their huge wealth of their experience of inclusion. However, this research was word limited and I was aware that I had to target my research to what I considered the most important aspect to be - the actual families: the parent and child and the impact inclusion had on their lives.

Finally, I must mention my own personal limitations. Working full time and having three children, and my father passing away during this process had a significant impact on my ability to find time to write and give it the dedication it deserved. I overcame this by dedicating specific days to study. In addition all of my annual leave that I have taken since starting this process had been used to do this Doctorate. My advice to anyone starting this valuable journey is to be realistic about life's potential twists and turns, understand that research at this level is demanding, be targeted, be disciplined and most important hold true to your heart that what you are doing will produce meaningful knowledge that is important to share.

Appendices

Appendix 1

Letter of explanation/invite to participants

My name is Vanessa Cleere. I am a student currently undertaking a Professional Doctorate in Education at the University of the West of England.

My research is exploring the current inclusion discourse, which is currently being played out in mainstream schools.

I will examine the life story a parent embarks on when they have a child with special needs in a mainstream school. I will examine the critical incidents that occur throughout this voyage. I will examine positive incidents and what made them positive and negative incidents and what made them negative. I will then ask each parent's child about their experience in mainstream school; again identifying critical incidents. Later, I will then compare the samples to see what, if any, commonalities exist.

I am inviting you to participate in this study. I hope that the findings of the proposed study will enhance knowledge of inclusion and facilitate an improved quality of life for people with differences.

If you would like to participate in the proposed study you will be required to give consent. We can arrange a mutually convenient time to conduct the interview. The interview will be taped. All information will be confidential and no identifiable data will be included in the study. All data from the interview will be managed, stored and disposed of as per the Data Protection Acts of 1998 & 2003 and the University West of England Compliance Guidelines. Also, your right to withdraw from the study at any stage is guaranteed.

If you would like to participate in the study, please sign the attached consent form and return it to me.

If you have any questions before making a decision, please feel free to contact me.

Kind regards

Vanessa Cleere

DECLARATION: I have read, or had read to me, the information for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

PARTICIPANT'S NAME:

CONTACT DETAILS:

PARTICIPANT'S SIGNATURE:

DATE:

.....
.....
.....
.....

STATEMENT OF RESEARCHER'S RESPONSIBILITY: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

RESEARCHER'S SIGNATURE:

DATE:

Appendix 2

Appendix 2 Learner Consent

Name.....

Vanessa has explained to me what her Doctorate is about and why she would like to have my views.

She has explained to me that if I don't want to take part then I don't have to. She also told me that if I do agree to take part then I could stop whenever I want. Vanessa has made it clear that she will show me her writing. She explained that I would then have the right to then say whether I agree with what she has written or if I would like it changed or if I want it deleted. She has also explained that she will change my name so that no one can identify me through her writing. My parents have been informed and they have given consent.

I agree to take part.

Signed.....date.....

Parent name.....date.....

Parent's signature.....

Appendix 3

SEN Timeline.

Year	Legislation	SEN Implication
1944	Education Act	11 categories of 'handicap'. Health Authority still responsible for the 'severely subnormal'.
1963	Newson Report	Recognition of inconsistency within secondary provision for SEN.
1970	Education Handicapped Children Act	All children under the LEA.
1970	Chronically Sick & Disabled Persons Act	Required LEA's to keep a register of disabled people and to provide services for them,
1978	Warnock Report	First time the term SEN mentioned. Replaced the 11 categories of 'handicap'. Five-stage approach for recognition and assessment established. Integration of SEN into mainstream considered.
1981	Education Act	Recommendations from the Warnock Report enacted . Introduction of the statementing procedure. Five stage approach adopted and categories of 'handicap' abolished.
1988	Education Reform Act	Intro of the National Curriculum
1989	Children Act	Includes register of 'Children in Need'. – recognition of children rights.
1993	Education Act	Promoted the education of children with SEN in mainstream. Class teachers responsible for SEN pupils in early stages.
1994	Code of Practice	Role of SENCO made statutory
1994	UNESCO Salamanca Statement	Inclusion for all children & adults
1996	Education Act	Parental Rights in terms of appeal. Time limited placed on assessment for statements (26 weeks)
1997	Green Paper: Excellence for All	Focus on inclusion and developing collaborative practice.
1998	White Paper: Meeting Special Education Needs	The draft / focus for the 'New' Code of Practice (2001)
1998	National Standards for SENCO	SENCO to take an active part in leading and managing staff.
2001	'New' Code of Practice	Management of SENCO role to be shared.3 stages of identification of need.
2001	Special Education Needs and Disability Act: SENDA	Strengthened rights of parents and pupils to access mainstream education - also extending civil rights.

Year	Legislation	SEN Implication
2001	Inclusive Schooling	Includes 'reasonable steps' and provides practical advice for including pupils with SEN into mainstream provision.
2003	Every Child Matters: ECM	Collaborative approaches- team networking towards the 5 outcomes . Working towards a social, as well as educational, inclusion
2004	Removing Barriers to Achievement	A sustained programme of action supporting integrated services and provision for all pupils.
2004	Children Act	Legal framework for the programme of reform – focus on vulnerable child. SENCO skills for implementing framework considered.
2005	White Paper: Higher Standards, Better Schools for All	
2006	Disability Equality Duty Scheme	'reasonable adjustment'
2006	Primary Review	Recommendations for future policy
2006	2020 Vision: The Children Plan	Personalised learning focus
2007	Inclusion Development Programme [IDP]	improve the skills of teachers by advising them on how to develop teaching strategies for children with special educational needs -4 yr programme.
2008	The Bercow Report	recommendations Government about transforming provision for and the experiences of children and young people with SLCN and their families.
2008	Lamb Enquiry	consider a range of ways in which parental confidence in the SEN assessment process might be increased; Final report due 2009

Year	Legislation	SEN Implication
2008	Back on Track	White Paper on Pupil Referral Units legitimises catastrophic breakdown of the SEN system
2008	SENCO Regulations	QTS & Accreditation
2008	Transition Support Programme	http://www.dcsf.gov.uk/everychildmatters/resources-and-practice/IG00322/
2009	The Steer Group	Learning Behaviour: The Report of The Practitioners' Group on School Behaviour and Discipline http://www.dcsf.gov.uk/behaviourandattendance/about/learning_behaviour.cfm
2009	Progression Guidance	Between 1 April 2008 and July 2009 the Department for Children Schools and Families (DCSF) are working in collaboration with the National Strategies to develop progression guidance for pupils with SEN/LDD including those working below level 1 of the National Curriculum.
2009	The Apprenticeships, Skills, Children and Learning Bill	

Year	Legislation	SEN Implication
2009	The Rose Report on Dyslexia	http://publications.dcsf.gov.uk/default.aspx?PageFunction=productdetails&PageMode=publications&ProductId=DCSF-00659-2009
2009	The Rose Review of the Primary Curriculum	http://www.dcsf.gov.uk/primarycurriculumreview/
2009	Achievement for All	
2009	Ofsted Review	Ofsted will report on school special needs standards
2009	Healthy Lives, Brighter Futures	http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094400
2009	The White Paper	<p>Your child., your schools, our future</p> http://www.dcsf.gov.uk/21stcenturyschoolssystem/ (video)

Year	Legislation	SEN Implication
2010	Equality Act	<p>http://www.direct.gov.uk/en/DisabledPeople/RightsAndObligations/DisabilityRights/DG_4001068</p>
2010	Ofsted Review: SEN	<p>http://www.ofsted.gov.uk/Ofsted-home/Publications-and-research/Browse-all-by/Documents-by-type/Thematic-reports/The-special-educational-needs-and-disability-review</p> <p>This review was commissioned to evaluate how well the legislative framework and arrangements served children and young people who had special educational needs and/or disabilities. It considered the early years, compulsory education, education from 16 to 19, and the contribution of social care and health services.</p>
March 2011	The Wolf Report	<p>http://www.shift-learning.co.uk/useful-links/200-wolf-review-summary-.html</p> <p>The Wolf Report, commissioned by Education Secretary Michael Gove and carried out by Professor Alison Wolf, is an independent review of vocational education</p>
2010	SEN Green Paper	<p>New Coalition Government seek the views on SEN</p>

		[Public Consultation 13 weeks]
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Appendix 4

Causal contextualization explanations from each story

Analysing each story (An example)

Causal Contextualisation from each story
John and Tracey

Negative Experiences	My Initial Analysis
<i>His teacher said, 'I have been a teacher for 30 years and I just can't quite fit John into a box.' She just couldn't work it out.</i>	Lack of understanding of difference. Question the value that is attached to difference.
<i>I felt teachers didn't understand him and accused him of being difficult. This had happened right through nursery and no one understood that it might be autism</i>	Lack of understanding of difference. Lack of value attached to difference.
<i>No, actually there is more awareness but absolutely no more understanding or support of autism; this hasn't improved in the last 10 years.</i>	More awareness of autism. Lack of understanding of differences. Lack of value attached to the value of differences within schools.
<i>I was chronically bullied by my best friend and felt that I was not understood.</i>	Feeling different and disempowered.
<i>I wasn't understood by my headteacher. I bought a lot of rage and upset into things. I acted out a lot. I felt the headteacher understood the other boys better. My friendship group had dispersed and they started to hang out with new people and I started to lose friendships. I didn't feel understood.</i>	Feeling different and disempowered. Lack of understanding and value attached to difference. Sense that behaviours are different than the 'norm'. A sense of being managed.
<i>Her eyes glared into my soul. She almost penalised me for doing it my way. It was unheard of how I explained things differently.</i>	Lack of understanding and value attached to differences.
<i>It's absolutely undone John.</i>	Disempowering. Damaging ones wellbeing.
<i>The teachers haven't got time to read about or support the individual. It is an exam cattle market.</i>	Positioning of differences in schools and the value attached to differences. Competing agendas within a school.
<i>Most of the time I feel like a pain. It is boring me just thinking that. I would ring at reception and before I even said my name they would say hello Mrs Jones and out of 3000 parents they could identify me; this is rather embarrassing 'John has lost all his friends because it's a pecking order no one wants to be seen with the person that is not coping or is different.</i>	Fighting the system by constantly ringing as needs are not being appropriately met. Feeling different than other parents. The value of differences diminished within a school. Feeling disempowered.

<i>One teacher called me names such as 'you plank' I felt disgusted and furious.</i>	Feeling very different. Lack of understanding and value attached to differences. Lack of teachers training.
<i>He struggled to understand multiple instructions and some people started to call him, 'thick'. I felt teachers did not understand him and accused him of being difficult.</i>	Feelings of difference. Feeling misunderstood. Lack of understanding of differences.
<i>My friendship group had dispersed and they started to hang out with new people and I started to loose friendships. I did not feel understood.</i>	Lack of peer group. Lack of being understood, feeling different.
<i>You have to go and speak to number 10 Downing Street. The teachers' hands are tied. Their hands are tied they are being told what they need to teach. Who's got time in a school of 1500 students to really seek out the individual? It's not the teacher's fault. I'm not actually being negative about the teachers it's got to come from higher up.</i>	Competing agendas. There may be more pressing agendas within a school environment that may be considered more important than the value attached to differences. The concept of differences is seen as less important.
<i>Since joining this school John has had to go under Children and Mental Health Service (CAMHS) twice. He now has a serious mental health condition, which were not there before.</i>	Mental Health episodes.
Positive Experiences	My Initial Analysis
<i>There was a massive improvement when I attended this school. This is because I had friends who could relate to me.</i>	Feeling as though he belongs and is part of a peer group. Differences recognised.
<i>The SEN department there was brilliant and because John is high functioning he was actually in nine top sets. This school was a good place for John.</i>	Differences valued, recognised and celebrated. The curriculum was able to be flexible to match John's needs.
<i>I felt connected. It made me a stronger person.</i>	Empowered, a sense of wellbeing. Feeling valued. Feeling as if you belong.
<i>The outcome came as a wave of excitement. It was astonishing. They understood me. They knew me. I wasn't stupid and I could talk a lot more with people and hang out in a lot more groups. It made me feel better inside. They understood my autism.</i>	Feeling understood, Feeling valued, Feeling empowered, Good Sense of wellbeing, Celebrating differences, Differences valued.
<i>We analysed each other's moods and looked out for each other. I did not feel lost. It was good.</i>	Sense of wellbeing. Feeling valued and understood.

Causal Contextualisation from each story

Archie and Paula

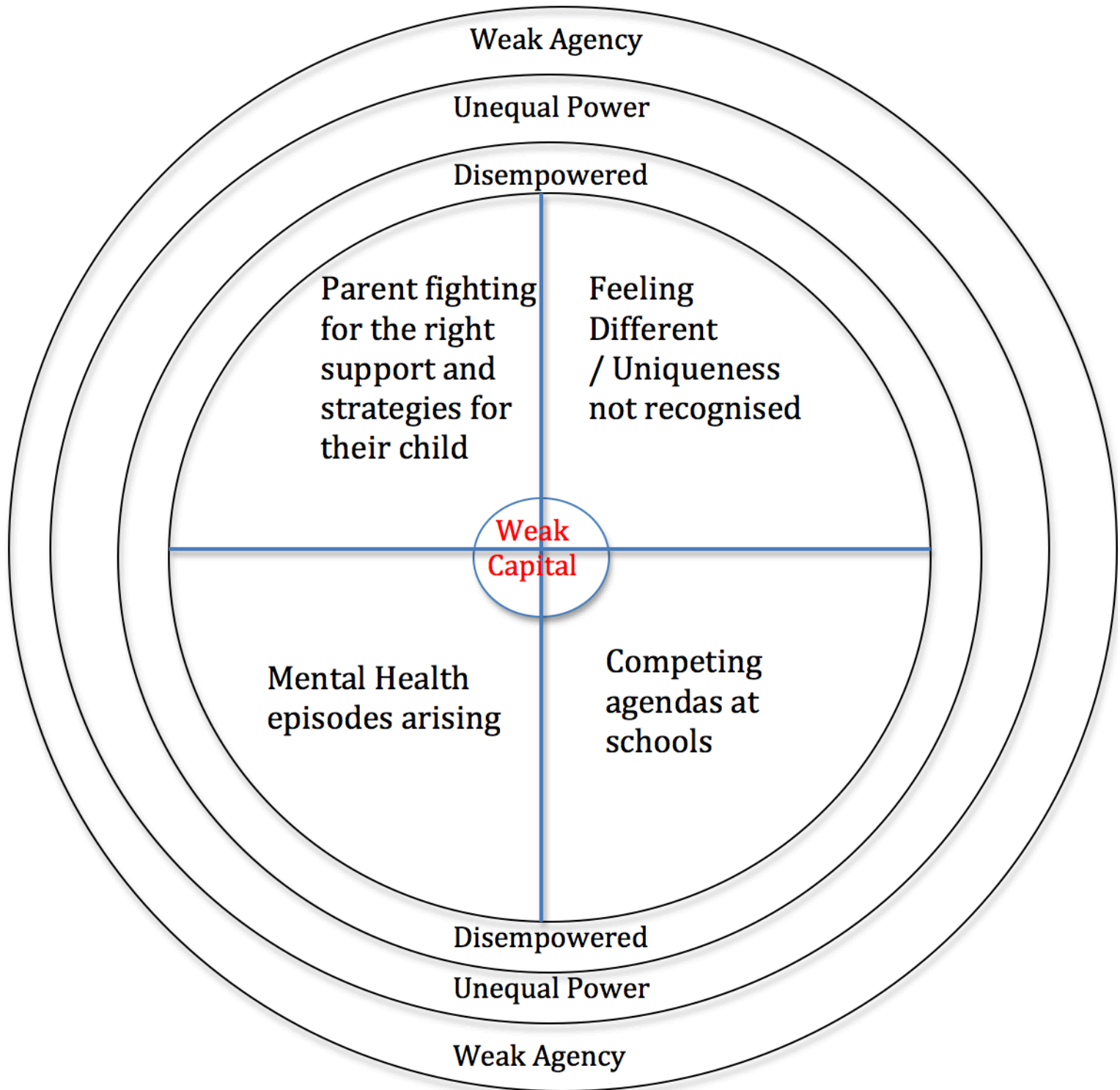
Negative Experiences	Initial Analysis
<i>When the nursery manager called me in to tell me that yes she did think his behaviour was different and there was something different about that. But she said she believed that in six months time whatever was wrong with him, he was going to grow out of.</i>	Lack of understanding of difference. Lack of value attached to difference.
<i>We did not have to fight for the ADHD diagnosis but we were 100% convinced- as was any other person who was medical who had met Archie were convinced that also he had Asperger's. It was harder to get this recognition but we felt that was important for his education, for us and for him, so we pushed for that and I would say that diagnosis probably took about a year.</i>	Fighting for a diagnosis. Different values attached to difference. Different power relations.
<i>The Nursery teacher did not understand Archie.</i>	Lack of understanding and value attached to differences.
<i>She used to shout at me for biting my jumper.</i>	Feeling different. Lack of understanding of difference. Lack of value attached to difference.
<i>The teacher really wasn't interested in Archie and wasn't that empathetic and really regarded him as a bit of a pain and a nuisance rather than properly accepting that he needed something a little bit out of the ordinary and that was not a successful year.</i>	Feeling disempowered. Uneven power. Lack of understanding of difference. Lack of value of difference. Lack of teacher training.
<i>I think it has been the expectation of the work and what is expected of him in terms of the quantity and the timetable, and with the homework that has been a struggle.</i>	Competing agendas within a school environment. Less value attached to difference.
<i>All the liaison comments that were coming home were very negative and not professional at all.</i>	Feelings of frustrations. A poor understanding of difference and weak value attached to differences.
<i>He also said to me that he knew that Archie hadn't had good teaching and if I was to hang on a year and send him back he could guarantee me good teaching the following year.</i>	Sporadic approaches to understanding and value of differences. Not a consistent picture.

<i>It was not a successful experience at all. His personality changed at home, he became very remote. He did not want to leave the house, he did not go out into the garden. He was very unhappy, he did not want to go to school.</i>	Changes to Archie's wellbeing; tipping into a mental health episode.
<i>He was very, very unhappy.</i>	Feeling different, feeling disempowered.
<i>He was not properly supported and guided.</i>	Lack of understanding of difference. Lack of value of difference. Lack of teacher training.
<i>He was so miserable and so unhappy that when he came home from school, I think it was the day after I had received that note in the diary and on top of that lots of other difficulties, he said that he wanted to kill himself. That was very difficult for us so he did not go back again.</i>	Mental health episode.
<i>I felt lonely and isolated.</i>	Feeling different, feeling misunderstood, feeling lonely, and having no peer group.
<i>It was just horrible there- they did not understand.</i>	Lack of understanding of difference. Lack of value of difference.
<i>I did not have any support from people. I was not understood.</i>	Feeling misunderstood. Feeling different. Lack of understanding of difference. Lack of value of difference.
Positive Experiences	Initial Analysis
<i>Good flexible, empathetic teachers.</i>	Flexible approach to school life. Having empathetic teachers. Valuing differences.
<i>They recognised that sometimes they might be in the middle of a lesson and if he heard a helicopter that it was okay to take sit in playground for five minutes to watch it. It was also, the communication between home and school.</i>	Valuing differences. Recognising uniqueness. Being flexible and innovative within he curriculum. Importance of good communication and having a voice and being heard.
<i>They had an acceptance that he was just a little bit different- but realised that he actually had a lot to contribute to the class.</i>	Valuing differences. Recognising uniqueness. Feeling empowered and able to contribute.
<i>We always felt really valued and really appreciated, also I gave a lot back to the school in return</i>	Feeling valued and understood. Feeling empowered and part of the educational journey.
<i>It was really kind, I was having a bad morning I think when I first came into school, and I was literally on the computer all day. She just let me, and I was on the computer all day. She knew</i>	Feeling understood, Feeling valued, Feeling empowered, Good Sense of wellbeing,

<i>that I was having a bad morning and she just let me stay on the computer.</i>	Celebrating differences, Differences valued.
<i>If it were something a little bit quirky he would allow it or facilitate it.</i>	Highly flexible and responsive curriculum. Valuing and recognising individual unique needs.
<i>We set up home school diaries, that has been a pivotal lesson of what works and what doesn't work. He has always had them and we have spent a lot of time every single day writing in those dairies</i>	Good communication. Understanding the importance of the parent being involved and empowered and part of the journey.
<i>Teachers who realised and knew the difference between the problem; accessing things and seeing what was naughty behaviour and what was autistic behaviour; because you can spot the difference.</i>	Good understanding and valuing differences.
<i>I had lots of friends in that year.</i>	Feeling as though you belong. You have a peer group.

Appendix 5

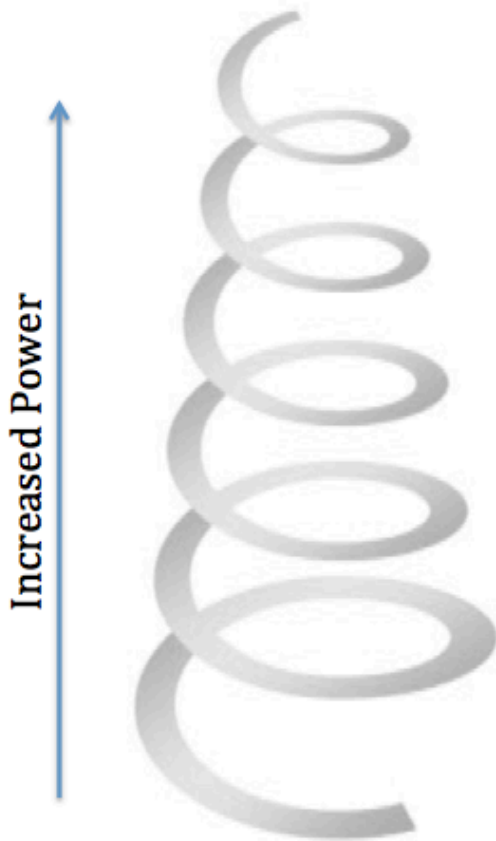
Connecting the themes.



Appendix 6
Connecting capital, power and agency.

Virtuous Spiral

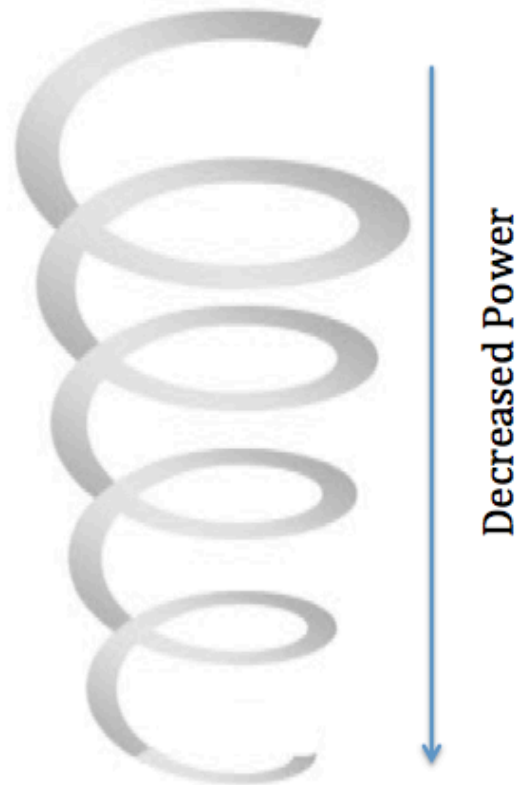
Strong agency – Where one is able to act and make decisions about their life



Language surrounding SEN is valued, resulting in good attitudes and good actions that lead to enhanced capital to trade with, increasing the power one has.

Vicious Spiral

Language surrounding SEN is not valued, resulting in poor attitudes and actions, that lead to less capital that one has to trade with, resulting in less power.



Weak agency – Where one is unable to act and make decisions about their life

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