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The Cockroach in the Cupboard, the Technical Amputee and Me:

An Auto-ethnographic Narrative Inquiry of Adolescence and Disability Identity; Storied by
Physically Disabled Women.

By,

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Abstract

Literature: Discourse around disability generally, is often dominated by medicalised and 'tragic' description (Shakespeare 1999; Goodley 2017; Campbell, 2009) and the research often carried out on disabled participants by able bodied researchers (Sheldon, 2017). This thesis critiques this view, and aligns with the Affirmative Model of disability described by Swain and French (2000). Research indicates that women with disabilities face a 'double disadvantage' in multiple areas (Rouso, 2003) through the intersection of the two identifiers (Wheaton and Crimmins, 2016). Particularly, experiencing adolescence as a female with a disability may impact identity development (King, Shultz, Steel et al, 1993; Magill-Evans and Restall, 1991) however the literature is fairly sparse. Adolescence is the key point in which the development of our identity occurs (Erikson, 1959-1963) this time can prove challenging for all young women (Bacchini and Magliulo, 2003; Ostrov, Offer and Howard, 1989; Simmons and Blith, 1987) and additionally young women with disabilities (Hanková, and Vávrová, 2016; Doubt & McColl (2003), this can impede on school attendance, academic, emotional and psychosocial development. Based on my own experiences as a woman with a physical disability, I considered it important to hear the voices of women with disabilities to appreciate their subjective experience of adolescence and identity, their response to a shared experience with a disabled researcher and their views on their identity.

Methodology: With a critical social constructionist ontology, this interpretivist study applied a narrative auto-ethnographic approach. From a critical disability studies and feminist theoretical perspective it hears the narratives of adolescence by women with physical disabilities. Participants included two (postgraduate) women who self-identified as physically disabled. Interactional narrative interviews were conducted, with the flexibility for the participant to engage with the researcher reciprocally, to ensure a shared experience. **Data**

Analysis: Stories were analysed using the Listening Guide (Gilligan, 2015) to reflectively explore their experiences and the meaning attributed to these in terms of their identity. Each narrative was analysed individually and various themes, contrapuntal voices, imagery and an 'I poem' were developed from each. An Auto ethnographic approach is used to capture my responses to the research experience. **Discussion:** Connections to the relevant literature are made and I concluded that the analysis of these personal narratives could provide helpful guidance to Educational Psychologists working with young people with physical disabilities. That is, in terms of their identity and well-being and influence systemic work with schools or communities, in terms of the way inclusive practice is encouraged through consultation and training. My personal reflections, on the research process which describe the influence of this on my own disability identity and practice conclude the thesis.

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Chapter 1

1.1. Introduction

This thesis begins by defining the terms used within it, (which may be unfamiliar to the reader) and by providing contextual definitions of key terms used throughout the piece. Following that, it provides the reader with my own Narrative Beginnings, which describe the rationale for my interest in the area and how this has influenced both the topics covered, and the methodology applied. Later, I outline my research questions and aims, leading onto a comprehensive review of the literature related to the experiences of disabled women, Mental Health and identity development. These are discussed in relation to my own experiences and key points are summarised at the end of this chapter.

In Chapter 2, 'Methodology', my ontological and epistemology position is described, leading into the theoretical perspectives, chosen methodologies, quality in research and finally the procedure. This section also details the process of the data collection and analysis.

The following Chapter 'Data Analysis' provides thorough narrative analysis (using the Listening Guide, Gilligan, 2015) of each participant's story; themes, characters, landscapes and contrapuntal voices are explored. My own reflections are incorporated throughout the analysis as I respond with my reactions to their stories on an emotional level. Similarities found between the stories are shared and discussed. The final chapter, 'Chapter 4: Discussion', incorporates a summary of my findings in relation to the literature reviewed, reflections on the interview process, limitations of the study and the contributions the research could have to Educational Psychology practice. Finally, a personal reflexive piece describing my research journey is provided.

1.2 Definition of terms

It is important to note that the terminology used within this thesis can have multiple definitions dependent on the paradigm which is chosen to view them. It is important to make clear the definitions used within the context of this research, I have declared these below:

- Disability: Disability is a term that holds various meanings and definitions to different individuals. For the context of this research, the terms disability/disabled refer to the integrated definition such as in the Affirmation Model of disability described by Swain and French (2000): *'... a non-tragic view of disability and impairment which encompasses positive social identities, both individual and collective, for disabled*

people grounded in the benefits of lifestyle and life experience of being impaired and disabled'. Further explanation of this view and a critique of it are provided in Chapter 2: Methodology.

- Impairment: this term is used to describe the physical nature of disability for the purposes of the methodology.
- Identity: According to Burke and Stets (2009) identity is the collection of meanings that define who you are when you occupy a particular role in society, are a member of a particular group, or you claim characteristics that identify you as a unique person.
- Mental Health (MH): The term mental health is termed as a state of well-being (WHO, 2014) Mental health is defined as: *'a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community'*. This ability-based definition is relevant to my research because I do not aim to address or analyse mental health in terms of diagnoses.
- Arthrogyriposis Multiplex congenital (AMC): *Arthrogyriposis is a general or descriptive term for the development of non-progressive contractures affecting one or more areas of the body prior to birth (congenitally)...The symptoms of AMC are present at birth (congenital). In most cases, affected infants have contractures of various joints. AMC affects approximately 1 in 3,000 individuals.'* (National Organisation for Rare Disorders, NORD)
- Scoliosis: *'Scoliosis is when the spine curves to the side. The spine can also twist at the same time. This twisting can pull the ribcage out of position. In most cases the cause is unknown.'* (Scoliosis Association UK, SAUK <https://www.sauk.org.uk/>)
- Ableism: Campbell (2009) and Banks (2015) defined the concept of ableism as: *'attitudes and barriers contributing to the subordination of people with disabilities in liberal society'*.
- Intersectionality: The notion of belonging to multiple identities; such as being female and black, female and gay or, in reference to this particular study female and disabled (Crenshaw, 1990).
- LGBTQ+: this refers to individuals who are Lesbian, Gay, Bisexual, Transsexual, Queer/Questioning and the plus refers to all other variations of sexuality. (Ok2beme, 2019) (<https://ok2beme.ca/resources/kids-teens/what-does-lgbtq-mean>)
- SEND: Special Educational Needs and Disability (SEND Code of Practice, 2014)

- Emic/Etic: Emic refers to being an 'insider researcher'; Etic refers to research conducted from an 'outsider' perspective. I am adopting both positions in my research.

1.3. Narrative beginnings

In this section, I describe my motives for embarking on this piece of research, on a personal and professional level. When engaging in narrative inquiry of any kind Clandinin, Pushor and Orr, (2007) recommend that a central element is the justification and detailing of the reasons why the study is important on three levels. Justification must cover the personal; the practical and the social. The personal justification comes from situating yourself in the study which can be done by providing 'narrative beginnings'. These detail my relationship with, and interest in, the inquiry. Further justification lies in the practicality of the research i.e. how it will be insightful to changing the practice of Educational Psychologists. Finally, the third justification requires a researcher to think about the larger social and educational issues the study might address. The narrative beginnings provide context for this inquiry on all three levels. They provide a clear explanation of my intentions and the aims I wish to achieve.

I am a disabled female Trainee Education Psychologist. I have Arthrogryposis Multiplex Congenita (AMC). This is a condition which I have had since birth and one that means that I am physically disabled. Naturally, I have faced, and do face, barriers both physical and social as a result. I experienced a lack of inclusion in school and lack of support socially and emotionally particularly during adolescence. I was not identified by anyone other than my parents as being disabled in the social sense. Identification of my disability came from a medical diagnosis, surgery, recovery, physiotherapy, reasonable adjustments and a statement of educational needs. On reflection, I believe that this, alongside wider ableist and patriarchal societal influences, had an impact on my well-being and identity development as a disabled woman. I would highlight adolescence as the most difficult period of time in my life thus far; in terms of socially and emotionally managing my disability. I began secondary school with being denied a place through the statutory SEND process. Immediate discrimination and rejection proved an unhelpful starting point where staff pupil relationships were concerned. Midway through secondary education I had surgery; I began to experience both anxiety and depression, in turn I had very poor self-esteem. In school, I was at times isolated from my peers and at others had unnecessary 1:1 support which impeded my social abilities. Autonomy over these decisions was not part of my story. Therefore, when planning the research, I chose to focus on adolescence.

Beginning my Educational Psychology doctoral training aged 26 provided me with insight into topics such as; social constructionism, disability models, narrative psychology, othering, disabled people as a marginalised group and inclusion. My training makes up the only teaching I have ever received on the subject of disability and lead to intense and emotive reflection of my past experiences. I was angered by lack of access to my own school, information, community, identity and my own history as a disabled woman and I made links to my own experience as a disabled adolescent. Notably I rejected my disability status and had a lack of shared experience during this time as the only physically disabled person in my family and social group; why was this?

During my placements, I observed how other young people seemed to reject support, want to pass as able or struggle emotionally with their disability identity in their adolescence. Further questions emerged regarding the lack of progress that has occurred in the time passed between my adolescence and theirs. These factors influenced my choice of topic for this thesis, my positionality and the methodology. As a result, I was interested to explore other women with disabilities' narrative of this crucial period of development through their stories. I was driven by a need to share the experiences of other disabled women, to give them voice and to impact Educational Psychology practice. With this in mind, the study will achieve to the following aims:

1. To actively listen to the stories of disabled women reflecting on their adolescence who self-identify as physically disabled
2. To develop an understanding of the participants' identity during this time period through their stories
3. To reflexively analyse and interpret these stories, as a disabled researcher, and to story the shared experience of the research process
4. To give the participants a much needed 'voice' with the aim of the research process being emancipatory for them

With my personal experience as justification, the research has an emic/etic stance; part of the research will be to explore stories through including my own reflections and experiences to facilitate an interactional narrative interview. My experiences and reflections will be used throughout the analysis through the use of an auto-ethnographic approach.

1.4 Literature Review

1.4.1 Overview

For the context of this research, it is important to recognise the rates of physical disability in the population; there are 14 million people in the UK who have a disability: 20% of men and 23% of women are disabled (Women's Budget Group: Disabled Women and Austerity). On review of the literature, I found that research including women and girls with physical disabilities are sparse. Research that includes their stories, experiences and which engaged them in the research process, even more so. This information thickens a narrative around the lack representation through the limited qualitative and quantitative data available. This suggested to me that the experiences of female adolescents with disabilities are largely underreported.

Being female and disabled is something which Rousso (2003) termed a '*double disadvantage*' in the '*Education for all*' campaign report, information collated on a global scale for UNESCO. Rousso's paper, which is referred to throughout this chapter, proved a great influence in forming the literature review. It highlighted to me the alarming scale of the social inequality faced by the demographic I am part of, work with and will engage with in this study. That is aside from the practical implications of impairment, (for example, missing school due to physiotherapies, surgeries, illness and appointments, access and pain) which might impact on factors such as self-esteem, efficacy and identity; all of which impact on a person's lived experience. Furthermore, there appears to be a lack disability research carried out by disabled people which, based on Rousso's review, could be explained by multiple means, such as less access to higher education, socioeconomic status, lack of expectation to succeed in education and so on.

Through incorporating all of the above, the research will focus on the areas of Disability Studies (the examination of disability as a social, cultural, and political phenomenon) and Feminist Research. A lack of 'joining up' of these two theoretical perspectives of feminism and disability studies within the research has been highlighted by Rousso (2003). She states that:

'Widespread cultural biases based on gender and disability; greatly limit (girls with disabilities) educational opportunities'

Rouso suggests that we know very little about this group because those committed to gender equity fail to consider disability, and those committed to disability equity fail to consider gender. This means that each discipline has unintentionally rendered disabled girls 'invisible'. Rouso explains that their 'invisibility' may in fact be their largest barrier to educational equality. It is my view that it would be a mistake to not reflect on our practice within Educational Psychology with regard to disabled girls and women and consider what efforts we are making to ensure they are visible and heard. Therefore I plan for the research to give voice to the disabled women who participate and for my voice to provide an insight for Educational Psychologists as a result of this. In order to do this I will respond to the following research questions:

1. What stories do two post-graduate women who identify as physically disabled tell about their experience of adolescence?
2. How do they reflect on these stories in terms of their identity development during adolescence and into adulthood?
3. How are both the researcher and participants affected by engaging in narrative interactional interviews?

With the context and aims in mind, the structure of the literature review is based on my reading around the subject of being female and disabled; it developed from this point to include some key reoccurring factors which connect with my narrative beginnings, my aims and research questions. They are as follows; *'Dominant Disability Narratives'* in which the disability context is shared. Following this are: *Disabled women: Intersectionality, Self-esteem and Mental Health in Women/disabled women, Identity Development, Disability Identity, Self-esteem and Mental Health in Disability and Impairment, Developing a Positive Disability Identity, Shared Experiences, Coming Out as Disabled: Comparisons with the LGBTQ+ Community* and finally, a Chapter Summary. Though the thesis has a soft social constructionist, narrative stance, I have chosen to incorporate a broad range of psychological stand points including cognitive, developmental and psychodynamic. It is my view that these theories have, and do, impact the population and therefore must be acknowledged when discussing the disabled female population. Though some of the paradigms used to view disability and development do not align with my own stance, they are present and impactful in disabled people's lives and therefore, I feel that it would be short sighted to dismiss them. I also feel that this provides a holistic presentation of what it means to be disabled and/or have impairment. Where possible, the literature has been deliberately

selected due to this being conducted or written by women and women with disabilities as I felt it was important to emulate the 'voice giving' aspect of my research throughout the chapters of the thesis.

1.4.2 Dominant disability narratives

Historically, the dominant narratives in disability have been of a medicalised nature (Oliver, 1990), meaning that disabled people are viewed as 'damaged' in need of 'fixing' and their experiences are grounded within their physical needs. Societally, this view remains pervasive however differing views have increased in prevalence across time; these will be discussed later in the chapter. According to Campbell (2009; In Banks, 2015) a female researcher in Critical Disability studies, negative messages given in society about disability are universal; *"Disability may be tolerated but in the final instance, is inherently negative. 'We are all, regardless of our status, shaped and formed by the politics of ableism' (p. 20).*

Campbell claimed that ableism can be explained as the aim of being able and therefore this perpetuates the idea that disability is the 'loss of being able'. Societally, this leads to a system in which mainstream society devalues disabled people and it privileges people who are able. In this view, a person's worth and intelligence are associated with being able, while disability is connected with stupidity and worthlessness (Pledger and Pledger, 2003). These stereotypes are thought to have a considerable impact on identity and productivity (Steele, 1997).

There is a tendency to dehumanise disabled people (Goodley et al., 2017) and in the media there appears to be a dichotomous view of disabled people as either 'heroes'; such as the rhetoric around the Paralympic legacy, (Goggin and Newell, 2000; Brittain and Beacom, (2016). Alternatively, disabled people are pitied, or worse, considered 'villains'; with the rhetoric around fraudulent disability benefit claims (Zhang and Haller 2013; McEnhill and Byrne, 2014). Hughes (2015) powerfully suggests that disabled people have been deemed as '*counterfeit citizens*' through a public mentality of resentment, perpetuated by austerity in the UK. Online, I see an emerging resistance from the disabled community around being used as inspiration porn; the sharing of content that shows how "inspirational" disabled people are when completing standard tasks, which is infantilising. Grue, (2016) explains that this has its basis in the medical model and it reaffirms the '*personal tragedy, overcoming adversity*' view of being disabled.

The impact of dominant disability narratives shouldn't be underestimated. Pledger and Pledger (2003) suggest that if disableism (discrimination, oppression or abuse due to disability status) is internalised, then accepting a disabled status as an 'unchangeable fate' can lead to blaming of one's self for having a disability in some cases. Furthermore, MH can

be impacted negatively by this. The societal assumptions described here, mean that individuals with disabilities are dually navigating both the internalised understanding of their impairment or label in addition to society's broader meaning making around their disability (Forber-Pratt, Lyew, Mueller and Samples, 2017). This is something which could impact somewhat on their identity as a disabled person and could be compounded by other identities carried by disabled people.

A more progressive view of disability was predominantly triggered by the disability rights movement in the 1970s and the actions of grass roots organisations (Shakespeare, 2018 p.12-13). This movement promoted disability as an identity and a culture; a community to be part of and to be proud of. The social model of disability was born out of this movement (Oliver, 1990).

The social model of disability and the rights movement lead to the development of 'Disability Studies' and later, 'Critical disability studies' theories. Disability studies is a discipline that aims to scrutinise the meaning, nature, and consequences of disability (Goodley et al., 2017). Researchers in this discipline, highlight the importance of separating Disability and impairment, as in the definition described earlier in 'Definition of Terms'. In part, this theory will inform my positionality and research methodology, it is explored in more detail within Chapter 2.

Unfortunately, though the disability rights movement was instrumental in policy and attitude change, the social model perspective remains subversive in comparison to the dominant disability narrative, and stories that challenge this view frequently go unheard (Saleebey, 2006). In my experience, these ideas of disability as a culture and a community seem to be more prevalent in research and academic literature than anywhere else, such as in education or in the media. I wonder how accessible these are to those in education and lay people?

In my view, this overview of the dominant disability narratives within society shows what a challenging landscape people with disabilities must live and develop within. It is also important to recognise that disability is varied, and it is essential to note that each disabled person's experience is different (Reaume, 2009) something that a narrative study such as this aims to express.

1.4.3 Disabled women: Intersectionality

Crenshaw (1990) developed the term intersectionality which refers to the notion of belonging to multiple identity groups, in the case of this particular study, being both female and disabled. The features of belonging to two identifies interlink and impact the person on

multiple levels. Intersectionality particularly relates to those of a minority group who may experience oppression through societal beliefs about 'norms'. Disability is deeply gendered (Fine and Asch, 1988) yet the literature on physically disabled girls in terms of intersectionality is sparse, providing justification for my research. Relatedly, Lloyd (1992) highlighted a dominance of male representation in schools and within disability studies alike. My rationale for selecting only female participants is partly due to the insider/outsider, auto-ethnographic nature of the research and the notion that I am better able to represent the group which I am from and that is female. It is not my intention to ignore the related challenges disabled men face in terms of identity, MH during adolescence and onward. However, I am not similarly connected to their experience and felt less able to interpret it and align it with my own story.

As Rousso's study suggested, despite improvements over time, it remains a disadvantage to be female alone; in terms of employment, expectations and judgement based solely on physical attributes. According to Wheaton and Crimmins (2016), who measured sex differences in physical function and disability globally, in all countries included, women had consistently worse physical functioning. The authors reported that women also tended to report more difficulty with activities of daily living, although differences were not always significant. Interestingly, Wheaton and Crimmins noted that education helped explain differences in their results. Where women with disabilities were better educated, their needs were less impactful on their activities of daily living. From an Educational Psychology perspective, this could mean that supporting adolescent girls to succeed socially and academically could lead to them having more social capital overall through being empowered.

Campbell (2009) suggested that disability experiences are naturally impacted by race. Non-white women with disabilities face more discrimination due to intersectionality. However, white women are at risk for internalised disableism, especially when struggling to adjust to an acquired disability with associated loss of white privilege (Campbell, 2009). It is therein not a leap to consider how experiencing oppression on two levels, and internalising negative beliefs about your identity, could impact your mental health.

1.4.4 Self-esteem and mental health in women/disabled women

In terms of women generally, according to a recent publication from the Mental Health Foundation (Mental Health Foundation, 2016) there has been a rise of 35% in ChildLine counselling sessions regarding anxiety, between 2015 and 2016. The Adult Psychiatric Morbidity Survey (2014) found that young women are *'three times as likely (26%) to experience a common mental health problem as young men (9%)*. *Young women also have*

the highest rates of reported self-harm and suicidal thoughts'. The authors suggest that the figures show that the mental health of girls and young women is *'in need of urgent consideration in the UK'*.

The current picture in Mental Health (MH) nationally, highlights an increased focus on mental health in adolescence (Transforming children and young people's mental health provision: a green paper within schools, DfE, DHSC, 2018). However, there is not a focus on the MH of disabled people or disabled women as part of this. Being aware of the possible increased vulnerability disabled young women may have to MH difficulties would be important to a practicing Educational Psychologist, in my view. Sadly, I cannot report statistics relating to women with a PD as they are not provided. This in itself provides indication to me that this is not a broad area of focus for professionals in the MH field, as it perhaps should be.

However, Hanková, & Vávrová (2016) conducted research into the emotional and social needs of integrated disabled students in the secondary school environment. Their study aimed to determine how university graduates with physical disabilities reflected on their emotional and social needs and their fulfilment in the secondary school environment. The researchers also measured how the participants described their place within the school 'class' system. The information was gathered qualitatively using semi-structured interviews and an interpretative phenomenological analysis undertaken, with some similarity to my own qualitative study. The results of Hanková, & Vávrová's study, showed that the emotions of the participants are predominantly determined by their poorly fulfilled social needs. The graduates experienced considerable distrust of their classmates, but also a definite reluctance of the teachers to accept their specific needs initially. The participants suggested that this linked to their lack of relational communication and collaboration, and their lack of shared experiences in school. This is something I have experienced in school myself, as I have shared within the narrative beginnings and something which I believe impacted my self-image.

In girls generally, it is the common rhetoric that they feel increased pressure to look a particular way and their self-esteem can be impacted (Clay, Vignoles and Dittmar, 2005). Bacchini and Magliulo (2003) conducted a multivariate analysis of adolescents' self-image and perceived self-efficacy during different phases of adolescence. Their research revealed that boys *"had a better self-image than girls and students at a mainstream secondary level"* and *"girls had better academic self-efficacy but a lesser degree of emotional self-efficacy"*. The authors also suggested that a central role was played by body self-image. They found that girls suffer advanced levels of stress during adolescence, possibly caused by educational factors, while the difficulties of secondary students overall, could be the result of the *'significant distance between the actual self and the ideal self'*.

Body image therefore appears to be a centre of the '*scheme of self*' and the authors claim that '*body self-image offers a solid foundation upon which the various aspects of self-image can be constructed*' (Bacchini & Magliulo, 2003). Further to this there are certain pieces of empirical research which have shown that females '*feel emotions more intensely than males*' (Brody and Hall, 1993; Stapley and Haviland, 1989), '*are more inclined to experience feelings of a dysphoric type*' (Kobak and Ferenz-Gillies, 1995) and that adolescent transition in females may include greater discontinuity, '*less optimism, and a relatively lesser degree of wellbeing than in males*'. With this in mind, if your body is different to the norm through having impairment, this may impact on body image, self-esteem and mental health in those who are disabled. According to Bacchini and Magliulo (2003) the variable that has shown the greatest number of differences between participants is gender, particularly '*at the level of the psychological self, the sexual self, and the perception of efficacy in coping with negative emotions*'. In terms of appearance, larger levels of displeasure among females is an outcome which has been highlighted within other research (Ostrov et al., 1989; Simmons and Blith, 1987) and interestingly this highlights evidence, through clinical observations, that there is an increase in the psychological conditions related to the body, such as eating disorders, among female participants. However, girls did show more ability '*in the area of aspirations and the perception of academic and regulatory efficacy*' (Bacchini and Magliulo, 2003). Given that, cultural and educational factors are also influencing variables. For example, the study was based in southern Italy, where females may have different cultural expectations by virtue of being female, compared to another culture such as UK or US culture. A similar study in the UK may present different results possibly because there may be less traditional gender roles, generally speaking. Given the evidence presented in the literature discussed above, it would be a reasonable observation that if your body is different, and/or you find it harder to maintain a healthy life style, due disability, your self-esteem and maybe self-efficacy can be affected, particularly as a young woman. But is that the case in research based in disability? Mona et al. (2005) linked the dissatisfaction disabled women can feel for their bodies, with the 'cultural obsession' with being physically perfect (which is consider the norm), they suggested that this expectation, in its extreme, can be complicit in the acceptance of mistreatment of disabled women.

In terms of identifying MH needs in disabled women, there may be an issue based on assumptions made about the disability experience. Campbell (2009) identifies that there can be a misattribution of psychological symptoms in disabled women. In other words, an assumption is made that their psychological symptoms are to be "expected" reactions to their physical disability. This is something which I relate to when I reflect on my adolescent, I believe that adults around me perceived me to be displaying 'typical teenage behaviour'

when I was experiencing depression for example. I recall a doctor explaining to my parents that it was 'very normal' for children to be depressed after surgery, with no suggestion of solutions, thus reinforcing that that it was expected. We can see here how being female and disabled can impact the MH of individuals, during their development and adulthood. I will now address what this means in the context of identity development.

1.4.5. Identity development

In psychology, the term identity is used to refer to conceptions of the self, expression of individuality, and versions of group affiliation (Dunn and Burcaw, 2013). Identities define us and can be focused on our past, present, or future (Oyserman et al. 2012). According to Erik Erikson's (1959, 1968) psychoanalytic theory of psychosocial development, adolescence is the time period most focused on developing an identity. However, identity formation is a lifelong process by some (Dekovic and Buist, 2005; Todorovic, 2002), but there may be increased levels of need at key points in that person's life, such as starting school or going through puberty (Zacharin, 2009). Erikson's theory comprised eight stages from infancy to adulthood which link with identity development (Table 1).

Stage	Psychosocial Crisis	Basic Virtue	Age
1	<i>Trust vs mistrust</i>	<i>Hope</i>	<i>Infancy (0-1.5)</i>
2	<i>Autonomy vs. shame</i>	<i>Will</i>	<i>Early Childhood (1.5-3)</i>
3	<i>Initiative vs. guilt</i>	<i>Purpose</i>	<i>Play Age (3-5)</i>
4	<i>Industry vs. inferiority</i>	<i>Competency</i>	<i>School Age (5-12)</i>
5	<i>Ego identity vs role confusion</i>	<i>Fidelity</i>	<i>Adolescence (12-18)</i>
6	<i>Intimacy vs. isolation</i>	<i>Love</i>	<i>Young Adulthood (18-40)</i>
7	<i>Generativity vs. stagnation</i>	<i>Care</i>	<i>Adulthood (40-65)</i>
8	<i>Ego integrity vs. despair</i>	<i>Wisdom</i>	<i>Maturity (65+)</i>

Table 1: Erikson's Stages of Psychosocial Development (Eriksson, 1959)

As depicted above, the stage of 'Ego Identity vs. Role Confusion' occurs within the largest part of adolescence, from about 12-18 years. According to Erikson, during this stage, adolescents search for a sense of self and personal identity, through an intense exploration of personal values, beliefs, and goals. This provides a relevant metaphor for the experiences individuals have during adolescence, and in terms of the participants within this research.

An alternative theory is Narrative identity (Singer, 2004; McAdams and McLean (2013) this theory involves the idea that a person's '*internalised and developing life story*' is reconstructed from their past and their imagined future. This leads to a life with a sense of '*unison and purpose*'. In narrative identity, psychological adaptation and development is the underlying factor of identity development. Studies into the connection concerning '*life stories and adaptation*' demonstrates that those who find '*redeeming meaning in adversity*', may develop more positive identities (McAdams, 2013; McAdams, Reynolds, Lewis, Patten & Bowman (2001). According to McAdams and McLean; '*redemption sequences in life stories signify a transition from emotionally negative scenes to a positive outcome or attribution about the self*'. In other words, adults who become improved '*from negative life experiences tend to engage in a two-step process of deep exploration of the events and then positive resolution*' (Pals, 2006). According to McAdams, (2013) individuals whom build life stories that comprise '*themes of independence and exploration*', *tend to enjoy increased levels of good MH and well-being*' (McAdams, 2013). In the context of disability, narrative identity theory gives space to individual stories which can allow for the varied experience of disabled people and to the experience of impairment. It also shows the importance of giving voice and independence, and the opportunity to explore disability to develop a positive identity.

According to Galvin (2005) we have to make stories about ourselves to create a sense of continuity and cohesion Sands (1996) and Ricoeur (1984) suggested that the 'narrative identity' is both a social construction and a means for exercising agency (Meekosha 1998, Thomas 1999). Therefore, this means that '*narrative may contain examples of dominant discourses as well as a submerged voice*' (Sands 1996 pg. 183), making it an integral part of the way I have chosen to present identity and disability identity development in this thesis and a vehicle to inquire about my participants lives in depth. Galvin (2005) suggests that "... *by revealing the powerful nature of normative values and by providing the mechanisms for challenging them, the telling and the exploration of narratives can provide the tools for emancipation*". My own research will use a narrative methodology to allow the participants to story their adolescence in their own words.

1.4.6 Disability identity

The idea of the formation 'the disabled identity' has been increasingly explored (Corker, 1999; Galvin, 2003). According to Darling (1970) the aims of a disabled people (and parents of disabled children) once seemed to focus upon normalisation, aiming to 'fit in' as best possible (Darling, 1970). However, in recent work Darling (2003) found that normalising can become an unachievable aim for most disabled individuals, which leads to them turning to what he terms 'Crusadership'. Crusadership means carrying out activities such as '*lobbying school officials, challenging doctors and creating new programmes*' alongside others within their communities. Darling used this finding to devise several factors of disability orientation these are: Normalisation and Crusadership (as discussed), '*Affirmation*' (individuals identify with the disability subculture in order to achieve their goals of access and the right to participate fully. They view their disability as their primary identity and in positive terms. The other categories are, '*Situational identification*', (people who appear to be capable of maintaining multiple identities, or to assume one that is appropriate at any given time), '*Resignation*' (individuals do not have the resources to achieve normalisation, but also lack opportunities for learning about affirmation) '*Apathy*' (being apathetic or completely uninformed) and finally, '*isolated affirmation*' (individuals who do not have access to subculture who may arrive at an affirmation orientation by themselves). This typology shows the variety of levels of identification disabled people may enact and shows how these can be impacted by external, societal factors.

Erikson's theory suggests that adolescents want to belong to a society and fit in which is connected with Darling's typology of disability. As Darling expressed, aiming for normalisation was an unsuccessful method, this was also acknowledged by Pledger and Pledger and Campbell as damaging to the 'self'. Following some of her narrative research into disability identity, Galvin (2005) concluded that the '*feelings of inadequacy, self-doubt, worthlessness and inferiority which frequently accompany the onset of impairment*' reported by her participants, are the result, not of a personal response to tragedy, but of 'internalised oppression' (Barnes, Mercer and Shakespeare 1999: 178). As previously discussed, adolescence is a phase of psycho-social development (Kroger, 2000) and there are other multiple explanations of why children with disabilities may find adolescent life more emotionally and socially demanding (Roshier & Howell, 1978; Shooter, 2005).

Riddell, et al. (2001) claimed that people with disabilities often have a limited range of identities to choose from, because of predetermined labels and assumptions they face within society. Relatedly, Erikson purported that forcing someone into an identity can result in rebellion in the form of establishing a negative identity, alongside feelings of unhappiness. In education, inclusion that focusses on the normalisation of disabled adolescents in schools may be 'pressuring' adolescents with PDs to fit within a mainstream identity, could therefore lead them to form a 'negative identity and feelings of unhappiness' described by Erikson. For myself, a greater sense of identity was developed through learning about the social and affirmative models of disability; this evoked a sense of belonging to a specific 'group', feelings that I cannot necessarily achieve within the able bodied community. This is something that is the case in research around minority identity development generally, acknowledged by Gill (1997).

If we consider adolescents with physical disabilities through both of the identity development theories above, aspects of teaching and inclusion, do not incorporate all that they perhaps should in order for them to navigate adolescence and form their narrative. For example, children with disabilities in the UK are generally not taught about values and beliefs of the disabled community (Shakespeare, 2009). They are not taught models of disability such as social, medical and affirmative models, nor disability rights or disability studies. Trieschmann (1980; 1988) indicates that education about the disability can help persons with disabilities improve their coping process. Educational approaches can assist people in learning about disability; factors that may affect the coping process; environmental situations and changes encountered in the community (Trieschmann, 1980; 1988). In my view, children with disabilities only experience the ablest version of this learning process and may experience barriers to life changes. In light of Erikson's theory adolescents are aiming for independence but disabled people can be limited by their lack of autonomy (physically or socially). Educational providers and Psychologists surely have a duty to understand the notion of entering adulthood as disabled adolescent and make it known widely within mainstream schools to encourage integration and put disabled adolescents into the narrative.

Some theorists (Gill 1997; Dunn and Burcaw, 2013) have been concerned with the '*development of personal identity*' as something which is ingrained '*in group membership and minority status*'; it has been studied cross-contextually within areas of; '*race, gender, and sexual orientation*'. As discussed, disability is considered by some as another identity; one that recognises '*individuals as part of a group and as members of a minority sometimes subject to prejudice or discrimination*' (Dunn and Burcaw, 2013). Though the term 'disability identity' is used, it is not defined well as a concept (Putman, 2005 pg.188). However, Putman suggests that '*there is general agreement that people experiencing disability often*

feel affinity with others who are disabled. Disability identity is reputed by Putman (2005) to be a key *'adaptive psychosocial construct in the lives of many people with disabilities'*, however there is a scarcity of academic research on the area.

During the period of adolescence, a failure to establish a sense of identity within society, can lead to role confusion (Erikson 1950, 1963). Role confusion involves the individual not being sure about themselves or their place in society. This perhaps shows how it may be crucial to ensure adolescents with disabilities get their social and emotional needs met at this stage, in terms of their feelings towards themselves; particularly as this intrinsic factor could impact their quality of life long term. Because disabled people's role in society is not made clear to them through societal or educational means, as described, they may experience 'role confusion'. This could impact on their wellbeing, as Darling stated in his typology of disability, there is no clear role societally for a disabled person that can be discovered alone. However with teaching and sharing of experience, opportunities for disabled adolescents could be broadened and their place in society given more meaning and significance, perhaps through narratives, as is the case within this research.

The aspects of development described here, mean it could be suggested that development might be interrupted as a result of impairment and disability in its wider context. Therefore this may change the trajectory of identity development for disabled people. Generally speaking, Erikson claims that the adolescent may feel uncomfortable about their body for a while until they can adapt and 'grow into' the changes. Adolescents with PD may be accepting the typical biological changes to their body whilst also grappling with the realisation of the permanence of their physical disability. In my view, this can be compared to the process of adjustment (Cohn, 1961) a model used to interpret the process of those who have acquired a disability. Livneh and Antonak (1997) posit that adjustment to disability is a process and not necessarily a linear one where persons with disabilities experience negative thoughts and internalised feelings (i.e., shock, anxiety, denial, depression) while they are attempting to learn how to adjust to the disability in a more positive manner (i.e. acknowledgement, adjustment). The researchers indicate that the coping and adaptation process is individualised and likely to vary from person-to-person and that adjustment to disability may be affected by factors such as age of onset, personality differences, beliefs and attitudes, finances, and so forth.

Stuntzner, (2017) noted that disability academics have tried to explain adjustment to disability as something that takes place with the aid of education about the disability and factors that affect the coping process (Trieschmann, 1980; 1988) or as that which is affected by environmental events (Scofield et al. 1980) as is theorised within narrative identity

development. Scofield et al. state that a person's adjustment process is influenced by the environmental events and components that surround a person. People, agencies, and other external forces (such as policies, legislation), have a role in placing expectations on people with disabilities about how they are to meet societal standards. People with disabilities often absorb these messages which then influence how they adjust to their disability and circumstances (Schofield et al. 1980). As described within narrative identity development theory, this can impact their identity development negatively.

1.4.7 Self-esteem and mental health in impairment

According to (Groce, 2004) almost 180 million young people between the ages of 10-24 live with a physical, sensory, intellectual or mental health disability globally. Despite this, topics such as self-esteem, self-image, and identity development are sparse within the literature regarding disabled adolescents (King et al. 1993; Magill-Evans and Restall, 1991; Shontz, 1975). Research about physically disabled adolescents has primarily focused on the adolescents' physical needs rather than their psychological presentation and development (Abrahamson, Ash & Nash, 1979; Seiffge-Krenke, 2001).

However, examples are available in research of the comorbidity of impairment in adults (Shontz, 1975). For example, Outcalt, Kroenke & Krebs et al. (2015) highlighted connections between chronic illness and Post Traumatic Stress Disorder (PTSD) and Depression. Andrew, Henderson, & Hall (2001) highlighted a correlation between service use for MH and disability and the WHO have analysed of the connection between impairment and MH (Scott, Von Kauf & Alonso et al. 2009). With a wealth of evidence existing for adults, there is evidently a need to explore further the experience of disabled adolescents in terms of their identity, psycho-social development, MH and well-being. Given that 50% of mental health problems are established by age 14 and 75% by age 24.2 (Adult Psychiatric Morbidity Survey (2014) a focus on supporting well-being, psychosocial development and identity in school could possibly provide an opportunity to address these barriers before their mental health is impacted upon.

The Mental Health Foundation (MHF), Mental Health Awareness Week report (2016) on relationships, may give some insight into the factors affecting mental health for young people, as good mental health requires strong supportive relationships (Kawachi and Berkman, 2001). The MHF state that there are certain factors which influence poor mental health within young people such as family changes, changing school, estrangement from family, bullying, isolation and pressure to look good.

These factors, though generalised, do make one question the long term impact of this across the life span of not addressing MH in adolescence. Particularly for girls with a physical

disability, who could be more likely to face several of the factors listed above in comparison to their peers due to the ableist views in society discussed in the previous sections and seen in Rousso's and Groce's global reviews. In terms of relationships and isolation, Knight et al. (2014) found that there appeared to be few opportunities (and little evidence of) physically disabled children and young people participating in mainstream social activities, in their qualitative review.

In terms of experiencing impairment, in their guide for parents and carers online, the Royal College of Psychiatrists (RCP) claimed that:

'Children with a long-lasting physical illness are twice as likely to suffer from emotional problems or disturbed behaviour. This is especially true of physical illnesses that involve the brain, such as epilepsy and cerebral palsy.'

It is suggested that serious illness or disability can cause considerable work and stress for parents, and that children who are ill, have many more stressful experiences than children without an illness (Rutter, 2008; Glazebrook et al. 2003; Hysing et al. 2007). The authors note that children can find these experiences distressing and these feelings can become pervasive. The RCP claimed that a child might have fewer opportunities to learn everyday skills, and to develop their interests and hobbies, which are factors described in the WHO definition, as being essential to positive MH. Though I find the deficit based language used by the RCP problematic, their guide provides an example of the impact impairment may have for the child, adolescents and families. The guide is medicalised and I would question its application to all children with disabilities and I am not sure it is a 'helpful' narrative. In my research I will aim to hear the participant's individual stories and experiences of postgraduate women and promote their strengths using a disability studies/affirmative model perspective so as to avoid the medicalisation of their disability status.

Adamson (2003) held the view that psychosocial development of adolescents with physical disabilities has been largely ignored. She conducted a study which examined the self-image of a group of young persons with cerebral palsy. The participants were interviewed and asked to complete a personality inventory. Interestingly this revealed that the participants viewed themselves in a positive manner and scored decidedly higher than a comparable 'norm group'. This positive view corresponded well with the findings of the interview.

Adamson's research leads to questions around why the perceived 'negative attitudes from others' did not appear to affect the young persons' self-evaluations at a time in their lives when concerns such as physical appearance, social skills, and abilities in general are of great importance. According to Adamson (2003) this scant interaction may mean the views

of family and other persons who are close to the adolescent may matter more than others. She states that the views of others:

'... would lead to fewer opportunities for these adolescents to shape and reshape their identities than for adolescents with more varied types of social relationships'. Adamson (2003) pg. 580

Findings such as those of Adamson challenge the view that a general attitude towards the self (either positive or negative) is formed very early on in life and therefore may not be as susceptible to the attitudes of others during adolescence (as may be thought by some). Further to this, the amount of social interaction adolescents with disabilities experience with non-family members, such as in the community, may be impactful on their sense of self. Some of Adamson's sample noted a lack of same age friends for example. Results reported by Blum, Resnick, Nelson & St Germaine (1991), were similar and showed that relationships with friends outside of school, and engagement in organised social activities, were exceptionally limited among the adolescents with spina bifida and cerebral palsy in their study.

Adamson suggested that further studies on self-image and the psychosocial development of adolescents with disabilities should focus on the both social interaction outside of their families, and the development of methods whereby adolescents can give voice to their own situation. Lack of participant voice is certainly a criticism of their work as the questionnaire used was standardised on the general population, and the interviews were semi-structured meaning less room for expression and interpretation of their views. Therefore it did not necessarily give space for the wider subliminal influences upon them such as ableism. However, Adamson's research highlights the importance of not making assumptions about the disabled experience, and of considering each person's story individually, which is my aim. From what we know about MH, the importance of conducting a study which aims to understand the experiences of disabled women in adolescence is clear. Efforts should be made to highlight ways in which their experiences in adolescence could be impacted by Educational Psychology practice, by training and policy making around MH and disability identity.

1.4.8 Developing a positive disability identity

It is thought that in order to '*survive and thrive*' in a society heavily influenced by ableism; women with disabilities must develop 'healthy disability identities' (Campbell, 2009). Gill (1997) in her work around minority identity development, suggested that there are steps' toward achieving a sound disability identity made up of individual, interpersonal and social factors. She suggested that the factors underlying disability identity development are;

'integrating into society', 'integrating with the disability community', 'internally integrating our sameness and differentness' and *'integrating how we feel with how we present ourselves'*.

Relatedly, Dunn and Burcaw (2013) who analysed narratives relating to disability found the following themes in the literature that lead to positive disability identity. Of the themes, *'affirmation of disability', 'communal attachment'* and *'personal meaning'*, were connected with a positive identity development; *'Personal meaning'* relating particularly well to narrative identity development. Similarly, to the theme of *'communal attachment'*, Doubt & McColl (2003), found that there was an impact on disabled participants' sense of *'integration'* through peer and staff support, negative reactions and inaccessible activities (as extrinsic factors). Their disability itself, strategies of self-exclusion, masking their disability, finding a niche and making fun of the disability, along with educating peers were intrinsic factors. Doubt & McColl concluded that the participants held *'a secondary place in their schools, as opposed to being fully included'*.

Disability identity involves developing with a positive sense of self, and a feeling of connection to and solidarity with other members of the disability community (Gill, 1997; Olkin & Pledger, 2003; Scotch, 1988). Gibson (2009) explains that stress is considerably reduced for all women with PD who develop disability identities. This is a similar concept to coming to terms with their needs which Cohn (1961) termed the *'process of adjustment'*. This is whereby those with acquired impairments go through stages in response to their impairment. The final of which is, *'adjustment and acceptance'* which is positively correlated with well-being.

Similarly, Enns (2010) described the purpose of identity development in disability, as movement from *'accepted internalised oppression to flexibility'* and positive attitudes toward or about disability. In short Enns suggested that, *'development of a disability identity allows disabled people to advocate for themselves and others'*. These processes have previously been shared within personal accounts of the disability experience; for example, Williams described how her disability, something she initially considered a private matter, is a significant part of her self-identity and is a major part of who she is as a person, (Williams and Upadhyay, 2003). The process is seemingly very personal therefore, the participants engaging in my research will have self-identified as disabled. This is rather than the definition being applied to them by myself as the researcher. According to Johnstone (2004) the term "disability" can be stigmatizing and disempowering when it is imposed upon them by others, something that is against the transformative, emancipatory nature of my research. Within the literature, the construct of a *'healthy'* (Campbell, 2009) or *'sound'* (Gill, 1997) disability identity hasn't been particularly critiqued, nor does it seem to have a distinct origin.

It is important to acknowledge that this must mean different things to different disabled individuals, and I do not use these terms with the intention to medicalise disability identity. Neither do I aim to accuse those who have not connected with the disability community, or haven't advocated for themselves or come to terms with their acquired impairment, of having an 'unhealthy, unsound or negative' identity. I think to do so would be limiting of the experience of being disabled. From my own perspective, the oppressive nature of ableism within society regularly impacts my thoughts and feelings about my impairment. At times I advocate for myself and others and sometimes I do not have the empowerment to do so. There is seemingly a fluidity to disability identity rather than a dichotomy of 'positive or negative' and it seems contextual in nature.

Using a construct such as 'healthy disability identity' carries the risk of the experience of disability becoming medicalised and measurable in terms of healthy and unhealthy, in need of support or not in need of support. If this concept was to enter the wider discourse, could it perhaps take power from disabled people and leave them vulnerable to these terms being oppressively applied to them? The connection between language (discourse) and power is well researched particularly in relation to philosopher, Michael Foucault (Hall, 2001; Thornborrow 2014). Wodak (2012) analysed this in relation to European immigration, in her view language and choice of language are part of identity construction (individual and collective), and we subconsciously speak and act in ways appropriate to the situation, because we have learnt how to do this from a young age. Wodak states that: *'All human identities are social in nature because identity is about meaning, and meaning is not an essential property of words and things: meaning develops in context dependent use, the power of those who can use language for their various vested interests... Language can be used to determine and define similarities and differences; to draw clear boundaries between 'us' and 'others'.* In the context of this research I will not be using the dichotomous terms mentioned above with my participants due to the potential power I hold over them as researcher to influence their views on their disability identity.

1.4.9 Shared experience

A key feature throughout this review so far is the need for shared experiences and connection to a group to obtain a positive identity disabled or otherwise. Shared experience relates to concepts such as collective participation and relatedness which can be linked to emotionality (Neville and Reicher, 2011). Many psychological studies express *'the importance of shared experience in terms of well-being and identity'* (Boothby, Clark and Bargh. (2014; Bastian Jetten & Ferris, 2014; Hopkins, Reicher & Kahn et al. 2016). For

disabled people, unlike those who identify with other minority groups, may not develop in an environment that includes other people who face similar discrimination (Bickenbach et al. (1999). If this is the case, there are no naturally available role models who demonstrate coping strategies and varying levels of pride in the disability identity. Shakespeare (1996) highlighted this as an issue within disability generally.

A lack of shared experience is certainly something that I experienced during my secondary school education. Sharing with others in a similar position may have helped me to form connections with people and view others as similar to me and perhaps those who I could've considered a role model. By this I mean a role model in terms of their ability to lead a functional life, for example, a successful working disabled woman, with a partner, and who perhaps had children. All of which were areas of my future I had concerns about in adolescence. In line with narrative identity theory, a role model may have helped highlight to me a different imagined future; one in which these events were a possibility for me.

According to Sheldon (2017) in a decade of working in the field of Special Education, he reports having rarely encountered a teacher, let alone a researcher, with a visible disability, either physical or cognitive. More generally, Sheldon explains that he has rarely encountered researchers in the field of education with any kind of visible 'difference' be it disability, gender, sexuality, weight, or other. I would second this having rarely encountered other disabled people within my career or schooling and I have created a shared experience within this research.

1.4.10 Coming out as disabled: Comparisons with the LGBTQ+ community

Some writers have referred to the process of acceptance of disability in terms of 'coming out', as disabled (Gill, 1997; Titchkosky, 2001), drawing a comparisons between 'coming out' in the LGBTQ+ sense. It is after all, a minority experience. Coming out, for disabled people, is a process thought of as a redefinition of the individual identity (Gill, 1997). This is achieved through rejecting the dominant discourse around the disability and adopting a positive recognition of impairment through embracing disability as a valid social identity (Linton, 1998). This act of claiming disability is sometimes also termed identity politics (Putman, 2005). Having come out, the disabled person no longer regards disability as a reason for self-disgust, or as something to be denied or hidden, but rather as '*an imposed oppressive social category to be challenged and broken down*' (Samuels, 2003). According to Swain and Cameron (1999) in their analysis, coming out involves a political commitment. In their view, adopting of a medical model of disability and being categorised by others as disabled does not count as coming out as disabled.

However, according to Samuels (2003) the analogy of coming out as gay or lesbian applied to disability, limits the idea of coming out itself. Samuels suggests that in both LGBTQ+ and disabled contexts, coming out can entail a variety of meanings, acts, and commitments. She claims that to come out to a person or group usually refers to a specific revelatory event. Where as to “come out” usually refers to the time that one first realised and came to terms with one’s own identity. This second definition is perhaps the most similar to the experience of accepting disability. Samuels suggests that the narratives of people with “hidden impairments,” similarly to those of other non-visible social identities, are overwhelmed with themes of ‘*coming out, passing, and the imperatives of identity*’ (Samuels, 2003). This is certainly something that I identify with, I have passed for able several times and I have come out to several people, each of these instances has been different. According to Thomson (2017), described how she had thought of her congenital disability as a “private matter” and did not identify with disability culture or disabled people. She did report feeling a ‘*special connection with disabled characters in literature she studied*’. This influenced her to become a disability scholar. Though positive, the experiences described by Thomson, perhaps add another layer and indeed a pressure, to young women with disabilities.

From personal experience, interactions about my disability (in terms of acknowledgement and support) from outside of my family held more meaning and were more impactful in the development of disability identity and self-image. For example, there is no element of ‘coming out to’ family as they have raised you or have been raised with you, there is no revelation aspect. However, I have observed that when I have ‘come out’ to others (teachers, partners and colleagues) the act feels both risky and powerful. The responses vary greatly and it carries an emotional weight, something that I was not mentally robust enough to manage in adolescence, hence the tendency to ‘pass’.

1.4.11 Chapter Summary

On review of the relevant literature, the following points were of in interest and provide scope for further research; there is a lack of the disabled women’s’ voice and experiences reflected within the research covered. There is also little to no link made between female disabled adolescents’ social and emotional needs and their outcomes. Research conducted by disabled authors, in this area, is very limited and finally there is limited research available within the discipline of Educational Psychology (many of the articles were found in journals such as the ‘Occupational Therapy Journal’, which highlights the medicalisation of disability). According to Sheldon (2017) education ignores the critiques offered by researchers in disability studies (in which many researchers have disabilities). And furthermore, Connor et al. (2008, p445) researchers in Special Education, claim that:

“...standard and widespread use of damaging labels and deficit-driven medicalised conceptions of disability that undeniably contradict[s] the views and life experiences of many disabled people..”.

Therefore, this ‘deficit-driven’ narrative is one which I do not wish to perpetuate, giving rationale for my aim to hear the individual stories of women with physical disabilities. According to Dunn and Burcaw (2013) *‘narratives that highlight issues of disability identity can give people with disabilities (and their peers: family, friends, carers and professionals) and the able, a source for understanding and learning from the psycho-social experience of disability’*. They claim that first-person accounts reveal and endorse appreciation for the common and unique factors that shape the experience of disability. This is something that I hope to achieve, in line with my aim for the research to have an emancipatory benefit for the participants themselves.

To summarise, the aims of my research are aligned with the findings from narrative research conducted with disabled people, shared experience and the concept of narrative identity development. I hope to highlight that the lack of acknowledgement of a ‘disabled voice’ in the literature disregards the notion *“Nothing about us without us”* (Charlton, 1998) a slogan associated with the disability rights movement. When applying this notion to research, Sheldon stated that *‘disabled people need to be intimately involved in the processes of research on and about disabled subjects’*. Relatedly, Sheldon suggests that disability cannot be studied without working closely with disabled people and allowing them to be directly involved in the research process. In drawing out the experiences of women who identify as physically disabled, applying my own reflections and applying psychology to this; I hope to engage the participants in a piece of research by disabled people for disabled people, in line with Charlton’s stance.

Chapter 2: Methodology

2.1 Introduction

The chapter begins with justification of my philosophical and ontological positionality which underpins the qualitative methodology used within this piece of research. It refers to social constructionism, interpretivist methods, my emic/etic position and feminist epistemology. Following this, the theories; feminist theory, critical disability studies and narrative, are detailed. Explanation of how these theories link to the research, and one and other, is provided.

Narrative inquiry, auto ethnographic and specifically the Listening Guide (Gilligan, 2015) approaches are described and I will discuss the reasoning of their application within my research. I refer to alternative methodologies which could have applied within the research and why these have been rejected. How the chosen methodology allows for participant stories to be heard and interpreted is detailed. The method of data analysis is described in terms of its theory base and its practical stages, which I implemented when analysing the interview data.

Following this, information regarding the procedural factors of the research are described, as are the ethical considerations made and the efforts made by myself, as the researcher to ensure rigour in research. These provide a clear picture of the way in which the research was carried out and the justification for the participants, and my own, inclusion in the research methodology.

In sum, the purpose of the chapter is to enable me to demonstrate a clear and valid methodology in response to the following research questions:

1. What stories do two post-graduate women who identify as physically disabled tell about their experience of adolescence?
2. How do they reflect on these stories in terms of their identity development during adolescence and into adulthood?
3. How are both the researcher and participants affected by engaging in narrative interactional interviews?

It also adheres to the following aims:

- To hear and understand stories of adolescence from female Post-graduate students who self-identify as physically disabled
- To develop an understanding of the participants' identity formation during this time period through their reflective stories
- To experience and analyse, as a disabled researcher, the shared experiences within the participants' stories
- For engagement in the research to have an emancipatory benefit for the participants through voicing their stories of adolescence and disability

2.2 Positionality: Ontology and Epistemology

2.2.1 Ontology

Ontology is the nature of reality in other words; what can be known (Scotland, 2012); Hepburn, 2003; Silver, 2013). Scholars suggest that there is a 'spectrum' when we consider ontology and how we view knowledge, the extremities of which are realism and relativism (Morgan and Smircich, 1980 p.492). Realism would mean there is a way in which we accept a tangible truth that can be externally measured (Morgan and Smircich, 1980). Whereas, Relativism is the view that reality is subjective and differs from person to person (Guba and Lincoln, 1994, p. 110). Relativism makes the assumption that knowledge, truth, and concepts such as morality, exist in relation to culture, society, or historical context, and are not definitive (Crotty, 1998, p. 42). A relativist ontological position can allow a researcher to document human experience and access meaning and understanding in a way in which participants are seen as '*active givers*', and are permitted a voice (Ponterotto, 2005).

From my narrative beginnings, it was clear that my research methodology must aim to hear stories of women with PD and interpret the individual human experience via these stories, alongside my own. Therefore, in terms of methodological assumptions, it was clear that quantitative approaches would not provide the level of personal and subjective depth necessary to fulfil my research aims because they are aligned with a positivist epistemological stance. Weaver & Gioia (1994) suggested that research that is positivist in

nature aims to *'transform empirical inquiry of meaning into an inquiry of truth'*. In this study, it is not my aim to verify a hypothesis and I am not searching for a truth within the participants' experience which can be applied to all members of the disability community. Furthermore, a quantitative methodology would not allow me to reflect on my own experience whilst being in the role of researcher due to its objective nature. Qualitative research however, holds that we can conduct empirical research into meaning without using this to *'ground further empirical study dealing with verification'* (Weaver & Gioia, 1994). I have applied a qualitative methodology in order to cultivate an enriched understanding of experience (Lewis, 2015) and to ensure that the participants' experiences and my own were honoured as 'real' and 'true' for us, whilst acknowledging that 'similar' stories can hold different 'truths'. I aim to acknowledge a subjective truth in these factors that realist positivist approaches would not allow me to access. In sum, the ontology I am working within, allows for the appreciation of the existence of multiple perceptions of reality, rather than forming a homogenous group, this was a conscious research design. This means that the research differs from the realist, positivist, and assumptions which license objective, often medicalised and measurable understandings of disability. Each story of disability is different and this must be reflected in research.

2.2.2 Social constructionism and disability

The ontology of disability is much debated (Vehmas and Mäkelä, 2009). The definition of disability which I have adopted in this research is affirmative and integrates disability and impairment. This is largely social constructionist ontology, which has informed my positionality. In terms of my research, social constructionism gives space for the concept of a narrative identity, the female experience and the experience of member of a marginalised group such as being female and disabled. Social constructionism is also linked with the idea, or gives the possibility of social change through the actions of a group (Taylor and Whittier, 1992) which connects to my research aims around shared experience and emancipation. However, though I have used the terms disability and impairment with different meaning, using 'impairment' to explain the physical nature of mine, and the participants presentation e.g. limb difference, scoliosis. I acknowledge that this differential is problematic within social constructionism and disability studies for the following reasons.

For example, Hughes and Paterson (1997) argued that impairment can be described in a way that *'assumes that our somatic sensations, such as pain, are discursively constructed'* or in other words socially constructed and thought of as conceptual. Best (2007) however, suggested that the standing and position of pain, raises considerable doubt about the validity of a social construction of impairment. Relatedly, Gill (1997) has argued that the issue with

the discursive perspective on impairment and disability is that '*embodiment is more than conceptual*'. In simple terms, physical bodies matter in disability studies and the experience of disability is an embodied experience. Disability can't be thought of as mutually exclusive to issues such as pain and unasked for physical limitations. In line with Gill's theorising, Wendell (1996) claimed that there is no recognition of, or space given to '*concrete physical realities that are confronted by people with disabilities within social constructionism*' (Wendell, 1996, pg. 45). In the context of this study I align with Best, Gill and Wendell, in that I disagree that disability is completely socially constructed as I do not wish to risk undermining the experience of my participants by dismissing any references to pain or physical difficulty as a concept. Anastasiou and Kauffman (2013) articulate why this view is problematic, and very critical of the separation of impairment and disability. They suggest that by denying the underlying biological conditions of people with disabilities, social constructionists neglect a big part of disabled people's existence. The authors explain, and I agree, that this renders disabled people as '*not an individual with a full set of properties*', a half-person.

In short, when biological characteristics are not thought of as reality, disability becomes something which we do not feel strongly about either way (Kauffman, 2011), and the dichotomy between impairment and disability is methodological; it is not ontological. I have reflected this by using the terminology of impairment and disability separately within the narrative interview and analysis. Kauffman stated that '*acknowledging both the physical and conceptual sides of disability is paramount because a possibly flawed concept of disability can lead to negative socio-political shifts*'. This point is pivotal for my research because I aim for the participants to find the process transformative and emancipatory. If I were to impose a pure social model upon them and their experiences I do not believe I would achieve this aim. The affirmative model addresses the limitations of the social model through the realisation of positive identity encompassing impairment, as well as disability.

2.2.3 Epistemology

All research holds epistemological assumptions and epistemology can be described as the theory of knowledge and how knowledge can be generated, shared and understood (Barker et al. 2002; Hepburn, 2003). There are multiple ways of thinking within epistemology. At either end of the epistemological spectrum is positivist and Interpretivist epistemologies. The two suggest that there are opposing views of how knowledge can be gained. In order to establish to a 'social reality', interpretivist views reject claims in positivism that there is causality and there are laws. In other words, it rejects the idea that our experiences are measurable, as a universal existence (Darke et al., 1998). My research instead aligns with

the ontology of social constructionism; it is therefore interpretivist and holds the assumption that to make sense of the social world, knowledge is constructed as opposed to created. Social constructionists take interest in how knowledge is constructed and society is viewed as a subjective and an objective reality. Therefore, reality is created by sharing meaning (Andrews, 2012).

In the context of, disability research, Oliver (1992) suggested that positivist methodologies, using disabled people as subjects, have historically dominated disability research. He heavily critiqued this stand point due to its lack of inclusivity. Oliver claimed that taking on quantitative approaches can diminish the varied life experience of disabled people; this also denies them a voice. In my view, viewing disabled people as a 'subject' to be studied could be deemed oppressive; hence I chose not to develop a qualitative study which is co-constructed. Furthermore, the majority of research with the aim to understand the disabled experience, has been conducted by able bodied researchers, It has been done 'to' rather than 'with' the participants, as they are objective in nature (French and Swain, 1997). Oliver claimed that the positivist focus in disability research has led to the representation of disability experience being distorted; and that the link between research and social change has been seen as '*relatively simplistic and rational, adopting a social engineering approach to the policy making process*' (Oliver, 1992, Pg. 8)

Instead, interpretivist approaches suggest that there are multiple accounts of reality. Reality is subjective and individual meaning is acknowledged as subjective truth. Interpretivist approaches show appreciation of the fact that "*there are "knowledges" rather than "knowledge"*" (Willig, 2013 p.7). My research aims to appreciate a subjective truth in the participant's stories. I wanted to hear the participants' personal stories, unique to the owner of that reality and connect them to my own subjective experience. Whilst acknowledging other influencing factors on their stories such as societal and cultural structures, through the affirmative model. Further to this, in her social-relational description of disability, Thomas (1990; In Thomas (2004) put this succinctly as:

"Disability is a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing" (Thomas, 1999, pg. 60).

My research will be critical of any formalised, positivist, concept of what it means to be a woman with a physical disability, outside of using these as definitions (i.e. the age range included in adolescence, being female and disabled as defined by the participant). Interpretivists suggest that social reality is constructed through shared language (Willig, 2013). In simplistic terms, this means that through conversations/language and stories,

meaning is made. With this in mind, what may appear as the 'same' experience can be constructed in different ways; shaped by social, political and cultural influences. As referred to Chapter 1, this is highly important when considering disability which is an experience that crosses multiple cultural boundaries, no one disabled experience is the same. By adopting this epistemological position, I will be able to interact with the participants in a way which gives personal insight into their subjective experiences (Block and Weatherford, 2013). Specifically, narrative approaches, according to Lieblich et al. (1998) provide a paradigm which calls for '*pluralism, relativism and subjectivity*' for me to work within. Narrative's pluralistic nature will also allow me to explore the intersectionality of being female and physically disabled and to work within an emic/etic stance as researcher.

2.2.4 Emic/etic position

It is important to note that Oliver (1990) raised the critique that in disability research, both positivist and interpretivist approaches can be oppressive to the participants, due to their aims being led by the needs of the researcher, not the needs or agenda of the participants. He suggested that, interpretive research is '*just as alienating as positivist research because what might be called the social relations of research production*' have not changed (Oliver, 1990). The participants are not put 'first'. I have ensured that the participants within this study are put first in terms of the recruitment process and interactional narrative interview methods which will be described later in this chapter.

Oliver suggested emancipatory research that provides a critical inquiry, can in some way bridge the gap between positivist and interpretivist methods. Relatedly, Lather (1986, pg. 262) suggested that research that is emancipatory must '*illuminate the lived experiences of progressive social groups; it must also be illuminated by their struggles*'. And that a theory that is adequate for 'changing the world' must be '*open-ended, non-dogmatic, informing, and grounded in the circumstances of everyday life*'. Oliver suggested that the social relations of research development must also fundamentally change so that the researcher AND participants become '*changers and changed*' (Lather, 1986). Lastly, the methodology of research must also develop, and build upon trust and respect and include participation and reciprocity. By conducting this study as an emic/etic researcher I believe that I am going some way to ensuring the participants are constructing the data with me. I am going to allow for change and aim for the participants to gain from being part of the research, rather than 'taking' information from them, through interactional interviews.

As well as these different perspectives on meaning and knowledge, different positioning in epistemology also presents a variety of levels of researcher immersion which can be applied in research. For example, the researcher can be placed as either 'distal or proximal' (Goodley, 2011) from/to the participants depending on the epistemological stance of the researcher. In positivist research the expectation is to be impartial and detached from the data collection process or 'distil'. Contrary to this, interpretivist approaches, such as narrative, include the researcher as an active agent who is influencing the research process and therefore the data set. In my research I am positioned, to use Godley's terms, as 'proximal' to the participants within the data collection process.

Through my personal connection to the research and my methodology, I am placed within the world being studied (Wellington, 2015) where a social reality is being co-constructed between myself and the participants. This fits with the key aim of my research; to hear individual stories and to promote the voices of women with disabilities, whilst analysing our shared experience. I have adopted a relational approach to research with some parts of the study being drawn from life writing and auto-ethnographic practices. Therefore, it was important that the research was conducted *with* women with a PD not *done to* them, and that it was carried out by a female researcher with a PD. The possible risks and ethical implications of emic/etic research are explored in the 'Quality in research' section of this chapter.

2.2.5 Feminist epistemology

Due to the nature of the participants, the connection with intersectionality, being marginalised and oppression, the research has transformative aims and therefore feminist theory has influenced my approach towards research. Feminist epistemology is an unstructured approach to epistemology, rather than a specific theory (Lennon and Whittford, 2012). It is diverse and draws on theoretical positions that constitute the fields of gender studies, women's studies, and feminist theory. There '*is an emphasis on the epistemic importance of gender and the use of gender as an analytic category in discussions, criticisms, and reconstructions of epistemic practices, norms, and ideals*' (Stanley and Wise, 2002).

Linking with both social-constructionism and interpretivist research; feminist epistemologies consider the ways in which knowers are linked in social relations that are '*generally hierarchical while also being historically and culturally specific*' (Oliver, 1990). In naturalist feminist epistemologies (which focus on causal accounts of knowledge), there is a way of

taking on board the fact that ‘*knowers are located in “epistemic spaces”*’ (Nelson 1990; Antony & Whit, 1993). Primarily, this links to ways in which cultural and historical factors can enable, rather than distort, knowledge.

As an alternative to naturalised epistemologies, stand point theory emphasizes the ways in which socio-politically marginalised groups are in a position of privilege when it comes to understanding social structures. We can see how this is appropriate to females with disabilities, within a disability identity, identity politics and ‘coming out’ narrative. The theory draws on the ideas of philosophers Hegel and Marx (Hartsock, 1998), arguing that those on the “outside” of prevailing social and political groups need to learn both how to get along in their own world and how to get along in the dominant society. Due to this, they have an “outsider” status with respect to dominant groups, which allows them to view social structures and how they function critically, in a way that members of the dominant group cannot. This is how I would position myself in terms of my emic/etic stance as a disabled female researcher.

However, according to Hardsock (1998) you cannot just occupy the “feminist standpoint,” through virtue of being a woman. She describes the feminist standpoint as ‘an achievement’ rather than something innate. You can occupy the feminist standpoint by thinking critically about your own experience and its relationship to larger social and political structures. By having an auto-ethnographic element of my research I am required to be reflexive and critical of my own positionality, identity and the assumptions I hold; a stance which could be described by stand point theory. Stand point theory, seems particularly relevant to marginalised groups and therefore my participants; theorists suggest that this must be seen as essential to women, and those that are marginalised (Harding, 1992).

According to Oliver (1992) feminist research has probably made most progress in the disentangling existing ideological structures. That is that these epistemologies (at least feminist empiricism and feminist standpoint research) have also made progress in developing methodological strategies corresponding with the emancipatory paradigm that he described. According to Gallop (1989), three key fundamentals must form part of the emancipatory paradigm; reciprocity, gain and empowerment. Lather (1986) suggests that these three points can be built into research by ‘*encouraging self-reflection and a deeper understanding of the research situation by the research subjects*’. Oliver suggests that research of this nature should perhaps not aim for ‘*social change (transformation) through engineering approaches to policy*’. He claimed that it should aim to create ‘*change through empowering the participants and that the reciprocity will be used to trigger the empowerment*’. This is something which I aim to achieve in the interactional interviews and

involving the participants in reviewing their own contributions to the research, therefore empowering them through giving voice and attempting to eliminate the researcher/researched power differential.

2.3 Theoretical perspectives

2.3.1 Critical disability studies

The research will reflect Critical Disability Studies theory. As discussed in Chapter 1, Critical Disability Studies views disability as both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world (Goodley, 2013), and as a social and political definition based on societal power relations (Reaume, 2014). Critical disability studies emerged from the activism of disabled people in the 1970s (Shakespeare, 2006). It challenges approaches that medicalise physical, mental and sensory differences as *'being in need of correction, and instead advocates for both accommodation and equality for disabled people in all areas of life'* (Shakespeare, 2009). Critical disability studies aims to change out-dated notions of disabled people. This view has arisen in direct opposition to the dominant personal tragedy model of disability and impairment, and builds on the *'liberatory imperative of the social model'*, meaning that disabled people take ownership of the label 'disabled' and are in fact disabled by societies focus on the able - the dominant discourse discussed in Chapter 1. Critical disability studies has influenced my choice of methodology, interview technique and emic/etic stance as a researcher. In terms of Educational Psychology practice and education, links have been drawn between this methodology and inclusive practice. Bikelen (2000) analysed critical disability narratives from various sources. They presented four themes from their review in terms of inclusive practice, these were:

"resisting static understandings of disability; creating and finding contexts for experiencing competence; learning to recognize and resist normate narratives of disability; and honouring the experience of disability".

These reveal just how valuable the use of critical disability studies in narratives can be in terms of understanding the interaction of experience and inclusive practice.

2.3.2 Feminist theory

My research aligns to feminist theory in that it seeks to remove the power imbalance between the researcher and participants; seeks to change social equality and gives voice to the standpoints and experiences of women (Stanley, 1990). These factors relate directly to

my research aims and procedure, with their focus on transformative practice and giving voice. Garland-Thompson (2002) noted that many disability studies scholars simply are not aware, feminist theory and that feminist theory can offer profound insights, methods, and perspectives that would deepen disability studies. Equally, Garland-Thompson (2002) suggests that feminist theories often do not recognise disability as an identity that aligns with the category of 'woman'. In my research, it was essential to acknowledge to marrying of these two theoretical standpoints when considering my own experience and that of my participants; so as not to prioritise one experience over the other, or indeed dismiss one and opt for the other. This influenced my choice of narrative methodology.

I have therefore chosen to use the Listening Guide (LG) (Gilligan, 2015) which is a methodology that gives the opportunity to listen for multiple voices within the data. Further information on the structure and application of the LG is provided in Chapter 3: Procedure. The LG provides a valuable way of working reflexively with (critical and constructed) subjects and with *'translating epistemological conceptions of relational narrated subjects into research practice'* (Gilligan, 2015). This method has the potential to provide researchers with the resources, and structure, necessary to unearth insights into their research questions, to a comprehensive level of quality.

The LG and interactional interviews give space for the factors of giving voice and the interaction between me and the participants. Morris (1992) states that inter-subjectivity and encouraging interaction, rather than one-way communication with research, is very important. She claims that this allows the researcher to constantly compare their work with their experiences as a woman and a researcher, and to share it with those researched. Their opinions are added to the research, which might change it once more. Change is expected within narrative research and the LG provides process for me to combine narratives with reflection to reflect the change which occurs over the process.

In addition, the LG provides space for the role and voice of researcher to be evident in the research. Feminist methodologies such as this *'allow the researchers' involvement to have meaning and provide researchers the opportunity to uphold the significance of reciprocity between researcher and researched'* (Lather, 1991). In feminist methods like the LG, the researcher and researched are permitted to be active, co-producers of each other's work (Woodcock, 2016). Woodcock states that, *'cultural production is one route through which marginalised groups empower themselves'*. By creating a shared environment and conducting interactional narrative interviews, I hope to empower to women involved in my study. As a disabled woman and the author of this research I needed the data analysis to

provide my participants with agency, and one which provided me with a methodology that highlighted our unique narratives and voices. I feel that the LG allows me to do this.

According, to Woodcock (2016) the LG *'provides the resources and structure necessary to unearth insights to research questions in a comprehensive quality'*. Grounded in feminism, of the LG permits the researcher's participation to *'have meaning and allows for the democratic reciprocity between researcher and researched'* (Lather, 1991). Gilligan (2005, p.75) reflected on the consequences of the LG from a historical perspective, inspiring researchers to:

"create the conditions in which people can safely tell their stories to someone who is listening and who can be trusted to bring their voices into conversations about human experience"

As a qualitative researcher wishing to share the stories of my participants, the LG provides me and the reader with insights to achieve this aim. Therefore, in this study, the narrative methodology described in the following section, will align with feminist and disability theories alike.

2.3.3 Narrative methodologies

I have applied narrative practices through interactional interviews using the LG. Narrative inquiry is built upon on the epistemological supposition that individuals *'make sense of random experiences by the imposition of story structures'* (Nolan, Hendricks, Williamson et al. 2018; Bruner, 1990; Polkinghorne, 1988; Duff and Bell, 2002). Webster & Mertova (2007), explain that stories are constantly being restructured when new events occur because they do not exist in singularity, but are rather, shaped by lifetime *'personal and community narratives'* (Webster & Mertova, 2007). Importantly, through narrativity we *'constitute our social identities'* (Somers and Gibson, 1994: 58–9).

Narrative methodologies advocate inclusion and participation, making the participants stories the main focus of the study. McAlpine (2016) described narrative research as a set of:

"... sound methodological tools to the researcher who seeks to pay closer attention to the diversity of human experience and finds a good alignment between his/her epistemological stance"

It is a suitable way to explore, discover, and understand silenced stories (Clandinin & Connelly, 2000) which seems essential when working with a marginalised group. Nolan, Hendricks, Williamson et al. (2018), suggests that narrative methods depend on detailed

accounts of experiences in life, as they are described (or storied) by the participant. Narrative inquiry can highlight how disability is '*understood and lived out in social, cultural, and institutional narratives that shaped the lived and told stories of individuals*' (Clandinin and Raymond, 2006) which is in line with the critical disability studies paradigm. Being an emic/etic researcher will be beneficial as narrative inquiry allows for, or possibly relies on, collaboration between the researcher and participants, over time, in place/places, and in social interaction with environments (Clandinin & Connelly, 2000, p. 20). This aligns to feminist theory, for example Webb (1984) discussed how she shared her own experiences with patients, and noted how this seemed to have a positive effect and encouraged their rapport. Furthermore, Sfard & Prusak, (2005) suggest that narratives represent accounts of participants' lives that are already amended as they emerge, for a specific research purpose at the request of the researcher.

Narrative methodology has been used in disability research to some success; Valeras (2010) used narrative research methodology to explore the hidden disability experience. Interestingly in Valeras' research, the participants expressed the need for knowing what they had in common with other persons with a hidden disability. Importantly for this study, narrative can link with a structural stance by providing an alternate view (Elliott, 2005). As Elliott (2005, p. 125) notes narratives; '*avoid the extremes of both essentialist and constructivist views of self.*' It therefore is in line with my critical social-constructionist ontological position. A further advantage is that researcher created narratives are easily accessible to the reader, therefore the results of the research can be used in teaching and other practices, and may lead to '*alternative futures to the demographic of the study*' (McAlpine, 2014). Naturally, as with all methodologies, there are limitations. McAlpine et al. (2014) who researched identity construction suggested that representing identity through narrative is only one aspect of '*identity-as-action*'. Therefore, it is important to avoid the idea that someone '*is an identity*' and instead emphasise someone '*acting an identity*' (Sfard and Prusak, 2005). De Fina (2009) suggests that narrative analysis has paid a lack of attention towards the interview in an interactional context. De Fina argues that methodologies of analysis must not fail to consider the way in which narratives shape and are shaped, by the diverse contexts in which they are rooted, something which I hope to address.

Furthermore, participant narratives only acquire a limited number of experiences, which we as researchers, use to estimate a coherent story (Holloway and Todres (2003). Therefore, as the researcher I need to be mindful of what is excluded from of an individual's accounts, as well as inconsistencies which may exist across accounts, or hesitations/holding back in their accounts. This is particularly important as the study is at such a small scale, however the 'contrapuntal listening's' stage of the LG will give me some access to the 'unsaid'.

Due to the factors described above, some suggest that narrative remains, as Pinnegar and Daynes (2007, p. 28) explain, on the '*margins of academic work*'. Also, according to Scotland (2012), the existing 'meaning making system' into which we are born, alters our understanding of phenomena on a level that we are not aware of. Therefore, interpretive research can frequently neglect to investigate outside structural forces which impact our behaviour (Cohen et al. 2007, p. 26). Understandings are "*structured historically in the traditions, prejudices and institutional practices that come down to us*" (Taylor, 1993, p. 59). Therefore, participants might not be aware of invisible ideologies which could be guiding their actions. As the participants might not fully understand the forces which are acting upon their agency, their explanations of phenomena are incomplete (Scotland, 2012). In my view, it is the researchers place to explore these factors alongside the participants.

2.3.4 Auto-ethnography

As is made clear from my narrative beginnings, my own story and experiences were a driver for the commencement of this research. Therefore, working within social-constructionism and feminist stand point theory, I cannot be separated from the research or my position of being a disabled woman, thus, it felt it was pertinent not only to acknowledge this but to utilize it to make meaning of my own experiences and connect with my participants.

Thus, in combination with the narrative approach, the research procedure will contain aspects auto-ethnography. That is, as the researcher I will contribute my own experiences to the analysis of the data. This will include my personal reflections on the process as a shared experience, my experience of conducting the research and of engaging with the listening guide process, all in the context of being a disabled female researcher. Auto-ethnography compliments feminist methodologies as '*each aims to validate women's experience, reject hierarchies between the researcher and research participant, and embrace an explicit goal of transformation*' (Holman Jones, Adam and Ellis, 2013, p. 24; Ellis and Bochner, 2006). This is when applied in its traditional sense; the participants in my research will contribution will form the main data set for my study.

The auto-ethnographic component aligns with the relational aspects of the narrative and the LG, to thicken the narrative of both the participants and myself. I am not a participant in the research but more an invested narrator. I acknowledge my position and the power associated with being a researcher versus a participant, a differential which exists by default. I intend the auto-ethnographic elements of the research to reinforce the authenticity, by being explicit about my disability status throughout. Auto-ethnographic methodology has previously been applied successfully within disability studies research (Couser, 2005;

Castrodale and Zingaro, 2015). In feminist disability studies, this method can solidify a disabled community (Mitchell, 2000, p. 311). Mitchell stated that unifying disability portrays it as a respected '*way of being in the world*' and situates '*overcoming societal prejudice as the primary means to improve the quality of life for disabled people*'. My research aims to make meaning for the participants in this way by respecting their personal experiences and stories through listening to and interpreting how disability identity featured in their adolescence. My own contributions may highlight how my own '*way of being in the world*' is interconnected with theirs through identifying as disabled. Ellis and Bochner (2006, p. 433), explain that auto-ethnography '*wants the reader to care, to feel, to empathise, and to do something, to act*'. It is those divergent purposes that resound with feminist methodology (such as the LG) as '*feminist researchers share a commitment to self-reflexivity*' (Garland Thomson (2005, p. 1560) meaning, that an auto-ethnographic approach in this study is appropriate and is complimentary to the LG.

Relatedly, numerous feminist disability researchers write about their personal experiences of being disabled and/or acquiring disability in order to express how personal experiences counter leading ablest norms (Ghai, 2003; Thomas; 1999, Morris, 1992). They may do so through the process of auto-ethnography or alternatively a technique termed '*life writing*' (Block and Weatherford, 2013; Simpican, 2017). My approach to auto-ethnography is similar to '*life writing*', a key piece of the disability rights movement. Life-writing is an approach '*in which the researcher analyses personal experience to understand broader societal patterns*' (Anderson, 2006; Holman Jones et al. 2013).

However, Thompson states that whilst feminist disability researchers use auto-ethnography to challenge ablest stereotypes, particular types of life-writing within feminist disability studies '*tend to reaffirm the difference between abled and disabled identities*' (Thompson, 2002). Thompson suggests that to subvert this dualistic view, auto-ethnography needs to be applied differently by '*telling stories that resist a univocal model of disability*' (Ghai, 2003; Thomas; 1999, Morris, 1992). By combining auto-ethnography (through my interactions and reflections on/with the participants) with narrative processes, I have a methodology which expresses two individual stories of disability identity in adolescence, interweaved with my own contributions and stories. Each story is considered on its own merit, analysed individually which circumvents a '*univocal model*'. Moreover, auto-ethnography links reflections of the participants' past experiences with their current sense of '*self*' to connect their past and present (Bluck and Levine, 1998). Linde (1993) termed this process '*autobiographical reasoning*' which is a process of telling biographically your individual developmental history and according to Buckner and Fivush's (1998) '*autobiography is ... the way we make sense of what happened, and this is fundamentally a social-cultural*

process” (p. 486). This is an aspect of the research that should provide both myself and the participants with a transformative experience.

2.3.5 Selecting a methodology

On consideration of the methodologies described above, I needed to ensure the data analysis gave space for individual stories, my own reflections and the connection of the two in order to respond to my research questions. After considering more traditional methods of analysis such as Holistic Content Analysis, Analysis of Narrative and so on, I became aware of the Listening Guide (LG) (Gilligan, 2015). In her use of the LG, Gilligan was attempting to expose the identity and moral development of women. She used interviews and multiple listening's to come closer to each participant's experience. This is a method of analysing narrative data which is a '*multi-layered interpretive approach*'. The method has been traditionally used within the educational context and applied in range of multi-disciplinary projects (Brown and Gilligan, 1992; Mauthner and Doucet, 2003; Gilligan et al., 2005). It therefore seemed to be the ideal methodology to enable me to engage with my participants, to incorporate my reflections and give voice to my participants as my research aims describe. With its application to education, I hoped that it would also provide data that could influence Educational Psychology practice. Further detail on the procedural format of the LG will be provided within the next section.

2.3.6 Reflexivity

Given the methodologies I have selected, reflexivity in my practice is essential to the quality and authenticity of the study. Relatedly, Heidegger (1962) adopted the term “hermeneutics” which is used to refer to the interpretation of the meaning of texts, documents and social practices (Nolan, Hendricks, Williamson, and Ferguson, 2018). Therefore, the hermeneutic position that guided my research, determines that a researcher cannot remove themselves from their own historical, situated positionality; therefore I must recognise that any written interpretations are always thought of as perspectival. Through the LG, this approach is applied with intention and I will be explicit in these interpretations and my positionality by providing reflection boxes throughout the analysis of the data. Rather than this limiting the study, I am using this aspect to add depth to the study and analyse the presence of a shared experience through the LG. However, it is to be noted that regardless of sharing experience through virtue of being disabled, my experiences cannot be directly compared to those of the participants. My background experiences go some way to producing understanding through interactions with the narratives of the participants, but not all (Polkinghorne, 2007). It is not my intention for the participants to form a homogenous group as this, in my view, is reductive; the disability experience is varied and differs greatly person to person. In line with

my ontology, subjectively constructed meaning making through narrative (both by participants and myself) is an essential component of research when using interpretive approaches, and indeed a strength of it (Andrew, Squire & Tamboukou, 2013; In: Nolan et al.,2018). Reflexive positioning enables a researcher to allow their history and personal experience of a subject to '*inform the research process and enhance engagement with participants*' (Nolan et al.,2018) and Clandidnin and Connelly (2000) consider this to be a significant strength of using narrative inquiry. However it is important for me to make clear that I cannot know everything that influenced my knowledge formulation process, and that there are 'degrees of reflexivity' (Mauthner & Doucet, 2003, pg. 425).

Chapter 3: Procedure

In this section, I share the elements that were essential in the planning of this research such as; ethical considerations, the participants, and sample and pilot study. Following this I detail the process of carrying out the data collection; the narrative interview process, how I ensured quality in my research. Finally, I provide details of the Listening Guide in terms of it's procedural application.

3.1 Ethical considerations and recruitment of participants

My original demographic from which to draw the sample for this research was secondary age girls with a physical disability, due to the fact that they were currently living through adolescence. However when it came to gaining participants who would need parental consent, I was met with the barrier of identifying the participants as disabled from my own perspective; something that Johnstone (2004) considers stigmatizing and disempowering. As an alternative, these prospective participants could have been identified by their parents or carers, which would have taken away their autonomy and their decision to identify as disabled. I was also concerned about the impact of targeting a sample and 'pointing out' adolescent girls with PDs within my schools, via the Special Educational Needs Coordinators (SENCOs) or other means. Therefore, adult participants were targeted due to their ability to consent, identify and their ability to choose to engage with the research.

I successfully gained ethical approval from the University Ethics Committee (see Appendix 1), and initial contact was made with the participants via a blanket email (see Appendix 2) sent through a university system to all undergraduate students of a large university in the

north of England. It was then down to the participants to respond voluntarily. This system was chosen due it being the only cost and time effective method of targeting a large group of individuals. It was central to my research that the sample was gained through aiming at a diverse population, rather than a targeted disabled population. This was in order to allow disabled women to self-identify as disabled. However, I acknowledge that by targeting the university population, this means that statistically my participants were likely going to be of a specific background and by virtue of attending university, had a level of education and opportunity that many disabled women do not. For example, 12.0% of UK students disclosed a disability in 2016/17 (Advanced HE, 2018) this accounts for all disabilities, and for both males and females. This is out of approximately 700,000 who attend university yearly in the UK (UCAS, 2018). This emphasises my justification for not creating a homogenised group which would no doubt prove more exclusive than inclusive when compared to the general population.

Through the method of sampling, only one participant volunteered, the other participant engaged in the pilot study and her data was used within the research as a second participant, she was also a volunteer. The recruited participant, was provided with a consent form (Appendix 3) and information sheet (Appendix 4) with description and details of the study, via email. Consent was fully informed, so that the participant was aware of the nature of the interview, expectations, commitments and analysis of the study. Their competence to be able to engage with this type of study was assumed due to their level of academic study.

3.2 Managing the risk to the participants

In terms of the potential for physical and/or psychological harm/distress to the participants the research is considered to be low risk. However, as a narrative inquiry it is unstructured, this means that many topics can arise which are not necessarily predictable. This was the case and there were discussions around very personal details, experiences which could have been emotionally traumatic or physically traumatic (such as surgery and bullying). These aspects could have caused social discomfort for participants during the interviews; it was through a respectful approach to the interview that a safe, confidential and contained environment was provided to account for this. The information sheet also sign posted the participants to support services with the university, in the event that this was necessary. During the interview, participants were asked whether topics could be explored, meaning through the interaction, continual consent was gained and mutual respect was essential. Due to their age, I considered there to be a low risk of realisation of the long term impact of their physical impairment, as they are past the crucial developmental mile stones.

3.3 Confidentiality

I provided guidelines on confidentiality to both participants. There was an expectation of confidentiality of participants which was made clear in the interview. Recorded data was saved securely and the original recordings and transcriptions were destroyed following the analysis and finalisation of this thesis. Pseudonyms are used to protect the participants' identity throughout the analysis and discussion, other identifiers have also been changed in order to retain confidentiality such as details of their course of study or employers..

3.4 Pilot study and sample

A pilot study was carried out in order to test the methodology and interviewing technique. The pilot study was conducted with a colleague who volunteered to engage with the research, named Alex (pseudonym). Due to the richness of the data this provided, the pilot interview was chosen to be used within the main data set, with the participant's consent. In order to gain other participants, undergraduate students were the targeted group having recently experienced adolescence due to their age (generally speaking). I am aware of the disadvantages of choosing to use the pilot study as data and therefore not having the advantage of a pilot study to develop questions and practice the narrative style. Van Tellingem and Hundley (2001) claim that pilot studies are an important element of a good study design and although this doesn't equal success in a study, it can increase the likelihood. Pilot studies also fulfil a range of important functions and can provide valuable insights for other researchers going forward. The second participant in the research, gained through the recruitment process was a post graduate student who had heard about the study through word of mouth, following the release of the email. There were no further respondents to the recruitment email; therefore the research relied on accounts from two postgraduate women as participants. There is no procedural significance of involving only two participants however narrative interviews require a detailed and in depth of analysis and it was always my intention to have a very small sample (Maximum 4) due to time constraints around data gathering and particularly the analysis.

It was important for me to retain authenticity to disclose my disability identity to the participants for both the pilot and main study, in the recruitment process. According to Sheldon (2017) it may not always be harmless to disclose a disability, however, a '*strategic disclosure may enhance the validity of the research; conversely, it is hard to offer tools to transform reality when you are hiding a significant portion of your identity from your participants*'. Sharing this part of my identity was essential for the data collection to be relational and authentic, in that it is a piece of research by people with disabilities for people

with disabilities. Sheldon suggests that people with disabilities creating and doing their own research on disability, alongside those with a disability, as the main researcher, is the '*epitome of participation*'.

3.5 The Narrative interview

In order to engage with the participants in a familiar and 'safe' environment, I met with each participant separately at the university. On meeting Alex, she had prior knowledge of my disability as a colleague and needed little explanation, therefore I explained the narrative research process and how the interview would work. For Sarah, who was the participant gained through the recruitment process; I introduced myself, my research topic, the purpose of the interview and the format. As the interviews were interactional and narrative, each participant was asked to introduce themselves, describe their impairment and then to speak about adolescence by reflecting back on their own experiences. The confidentiality, withdrawal and the details of the audio recording were shared again verbally.

In line with the research aims, I guided them to discuss adolescence, being disabled and being female. I facilitated them where necessary (i.e. the participants commented, I don't know, or needed rephrasing of the question) however it was important for me to follow their lead in terms of what topics they raised within the general remit of adolescence to keep the authenticity of their stories. I asked them to extend on points they made, and explore topics they shared, to ensure I understood and had captured their meaning. At times however, it was likely that their responses were shaped by my own contributions to the interview as the interviews were interactional.

In narrative interviewing the aim is to generate detailed accounts rather than brief answers or overall statements (Riessman, 2008, in: Nolan et al.,2018). During a narrative interviewing Riessman recommends a technique that allows the interpretive process to begin during the conversation. This means listening in an emotionally attentive and engaged way, essential to attempting to '*enter the world as experienced by another*' (Nolan et al.,2018). I ensure that the climate allowed for storytelling, leaving long turns to speak than are typical (Riessman, 2008). I adhered to this in each interview and allowed one story to lead to another without correcting the participant or asking them to remain on topic. I looked for associations and meanings that might, together, link several stories. I reflected these back to the participant

during the interview, this can be seen in the transcriptions (Appendices 4 and 6). I also encouraged them to elaborate on their depth of detail.

A positive rapport was developed enabling the participants to tell their stories in their own way (Clandinin & Connelly, 2000; Ziebland, 2013). The participants were encouraged to share detailed accounts relating to their lives cross-contextually. I listened empathically to enable the development of a trusting relationship in which to share experiences (Stuckley, 2013 in: Nolan et al., 2018). This was essential in my research due to its auto-ethnographic nature particularly, as Gough and Madill (2012) explain, there is significant importance in using empathy when interviewing populations whose members are not used to having others show interest in their experiences.

As discussed in Chapter 1, disabled people, particularly women are a marginalised group and experience a lack of representation and equality, twice over, due to intersectionality. This highlights the importance of informing the participants fully of my own positionality and narrative beginnings as a disabled woman, so that empathy can be reciprocal. Unlike a conventional interview I shared my experiences when asked and related to the interaction at the time. I acknowledge that this influenced their responses to a degree. Because interpretive researchers produce theorised accounts that represent participant's sociological understandings (Danby & Farrell, 2004, p. 41), there are issues around ownership. For example, who owns the data, how will the data be used and how much control over the findings do participants have. Although participants are often given a voice; it is usually the researcher who decides upon the direction of the research, the final interpretation of the data, and which information is made public. I made this clear throughout the process and through email, shared elements of analysis with the participants post interview.

As expressed, I engaged reciprocally with the participants (for example where a similarity occurred in the story) and invited them to ask me questions relating to adolescence and disability towards the end of the interview. According to Berger (2001) this can add complexity to the narrative produced. I explored the experiences of the participants as they were told and events in need of further explanation were scrutinised in the natural flow of the narrative being told, as would happen within a conversation. Denzin (1989) suggests that there are two coexisting worlds which form the human experience these are the deep and the surface. One consists of everyday events and is available for others to see, the 'Surface'. The 'deep' on the other hand, contain personal thoughts and feelings characteristic to the inner-self which is at times, but not always fully, revealed to others. However, I am critical of this perspective in relation to social constructionism, which drives the research. The idea of 'worlds which exist' and the idea that there are thoughts and feelings that are 'innate' (not influenced by society) are opposed to a social constructivist view. Therefore in my research

the interviews do aim to delve deep beneath the surface of superficial responses to obtain 'true' meanings that individuals assign to events. They will acknowledge the complexity of the participants' attitudes, behaviours and experiences regarding disability, identity and gender; but all in relation to the social context. This will be shown through the data analysis and discussion.

Throughout the interview, I used prompts, delivered in the narrative context, to encourage details such as when, how and why events occurred, the associated feelings and how these experiences reflected on their identity as recommended by Polkinghorne, (1991). It was essential for me to use my judgment, empathy and respect in the inquiry in order to contribute to, but not dominate, the interactions. I used skills gained from practical experience of holding consultations in my work as a Trainee EP, especially in Sarah's case as we were unfamiliar with each other. According to De Fina (2009), many researchers, particularly those who apply '*conversational analytic or ethno-methodological approaches*' (Schegloff, 1997; Goodwin, 1997) regard narrative interviews as artificial and consider them to oppose naturally occurring stories. Based on these interpretations, I wanted to ensure my interviews were as conversational and naturalistic as possible with the aim of providing a richer and more interesting source of data and analysis. To end the interview, I thanked each participant, fed back how interesting I had found their stories and explained the next steps for them in terms of sharing my findings.

Post interview contact

Some narrative researchers consider the need for long term interaction with the participants to 'thicken' their stories (Creswell and Miller, 2000). Due to time constraints around this research, the participants in this research were contacted by email approximately 3 months post-interview in order to ensure that the retelling of their story was in line with their expectations and I, as the researcher had portrayed their meaning successfully. I did this in person with Alex and via email with Sarah, each of their responses were integrated into the analysis such as by correcting details or extending on meaning.

I felt it important to contact both participants to share with them my interpretations of the data and to explain the use of the listening guide. This was with the narrative principles and my research aim around giving voice to my participants, in mind. Checking back with my participants added to the collaborative nature and 'shared experience' aspect of the research, in line with my research aims. Both of the participants gave positive feedback, they were happy with the representation of their views and, particularly, the presentation of the i-Poems. They felt that the listening guide was an interesting and appropriate analysis for

their stories and were in agreement with the themes I had selected. Sarah pointed out minor inaccuracies within her story and this 'checking back' gave me the opportunity to ensure their verbal data had been transcribed as accurately as possible, meaning it represented their views as truthfully as possible. No new data was added through this step however it gave me confidence as a researcher that I had represented their voices ethically within the research. This stage of the research added to the reflexive nature of the research; instead of simply reporting facts or 'truths' that they had shared with me, I wished to actively construct interpretations of the data, and then question how those interpretations came about.

3.6 Quality in research

In all research, it is important to work within a framework that ensures quality and in this study I have adhered to specific ways of collecting and analysing the data which are described here, in the context of narratives. Generally speaking in terms of the quality of narrative research, notions of utterance and recipients can differ depending on the listener, and this naturally raises the question of whether the stories are true (Bakhtin, 1986). Moen (2006) states that when it comes to this critical aspect, it is important to remember a basic claim of narrative research that '*truth is subjective*'. This fundamental claim makes the question of whether the data is 'true' somewhat irrelevant, in narrative practices, '*there is no static and everlasting truth*' (Moen, 2006). Instead Moen explains that there are different '*subjective positions*' from which we experience and interpret the world (Peshkin, 1988; 1991). Denzin (1989) contended that narratives are fictional statements that, to a varying degree, are about real lived lives. According to Denzin, truths are constructed between the researcher and the researched and notions of facts, facilities, and fiction are aligned with this. That is that, facts refer to actions that are thought to have taken place, and facilities describe '*how those facts were lived and experienced by the interacting individuals*' (Denzin, 1989). Meaning that true stories, are those which are believed by the listener.

3.6.1 Dependability and reliability

Recognising the subjectivity nature of the participant's stories, interactional of interviews and the array of possible data interpretations; reliability is not considered an indication of quality in my research. Owing to my interpretivist stance, I analysed the data after being fully immersed in the entire research process. As a result of this, interpretation is embedded within the context the stories were told, thus affecting its replicability.

In terms of being replicable, the data was co-constructed with individuals, so change is expected to occur (Merten, 2015). The research/researcher does not look to gain the same information if the study is replicated. Such research does not look to claim a reliable form of truth through a scientific exercise, to gain replicable results and confirm a hypothesis. Instead it recognises stories of subjective experience available at that place, at that specific time (Goodley, 2011). Therefore, I do not make the claim that my data provides a reliable form of information. Data collection methods and recording of the research process promotes dependability rather than reliability, ensuring that my decisions and outcomes have enough detail for others to follow my procedures. I make this available to the reader through reflexivity and accessibility to clear procedures, transcripts and analysis to support dependability (Polkinghorne, 1988).

3.6.2 Trustworthiness and Rigour in research

According to Lincoln & Guba (1985) validity is a redundant measure for qualitative research. Narrative research therefore, can instead be assumed to be '*well-grounded and supportable*' (Polkinghorne, 1988: p.175). It produces likelihood, rather than certainty. Trustworthiness and credibility substitute validity in this case, providing accuracy and integrity, over truth and proving of a hypothesis. In this piece of research trustworthiness is promoted via researcher engagement and interaction with the participants. Considered more faithful to the participants' experience through reoccurring involvement, reflective and reflexive practice, I immersed myself in the research process, using auto-ethnographic processes and gathered together the quantity of data deemed necessary for comprehensive analysis (Lincoln & Guba, 1985, Merten, 2015).

3.6.3 Transferability and generalisability (external validity)

Narrative research relies upon smaller participant samples to seek richness of data over breadth. Riessman (2008) described this as a case-centred inquiry. As such, generalisability is denied in recompense for richness and 'thick' descriptions. Whilst smaller sample sizes may not be recognised as representative, in the context of this research they can be used to give voice to marginalised groups such as women with disabilities. Rejecting claims of generalisability was a considered rationale of my research, to ensure I deviated from assumptions that disabled people are a homogenised group. I did not wish to contribute to a worldview which approves generalised assumptions and, even if unintentional, prejudices. Instead the research purposely aims to challenge the dominant disability discourse often ascribed to people with disabilities.

Transferability is considered to be generalisability's qualitative parallel; it looks at how the findings may be applicable beyond the exclusive context in which the information was generated (Henwood and Pidgeon, 1992). I recognise that there may be some transferable elements in the data analysis, but it is not my intention to force shared experiences disabled female population. According to Moen (2006) having a 'thick' and rich data set that draws on the individual, their social context and hearing multiple voices in their accounts; the researcher enables readers to transfer information to other settings. By doing so they can determine whether the findings are transferable because of their common features (Creswell, 1998).

3.7 Transcription and Analysis of data

3.7.1 The listening guide process

I adhered closely with Gilligan's approach by using a three step model. Following the collection of audio data, *'the Listening Guide employs multiple and successive 'readings' of interview transcripts each time listening in a different way'* (Brown, 1998, pg. 33). I chose to use the three readings approach, which entwined reflexively created narratives, *'relational narrated subjects, with constructed and critical subjects'* (Woodcock, 2016). The steps I used are as follows:

Step 1: Listening for the themes, subthemes, events, chronology, protagonists, plots, and key characters. I noted major themes relating to my research aims, using elements of narrative analysis (Mishler, 1986; Elliott, 2005). I did so by marking each passage within the transcription which connected to another. Whilst grouping together dominant story lines, this reading also provided a practical guide for me to work reflexivity with the data (Mauthner and Doucet, 2003). In doing so, I examined how and where some of my own assumptions and views might have affected my interpretation of the respondent's words, or how I would write about the person later, as suggested by Gilligan and Brown, (1992).

Moreover, it was important to make clear that my observations that were referential, were constantly highlighted so that they formed reflexive narration (Stanley and Wise, 2002, pg. 144). With this in mind, I interpreted each utterance that I selected from the full transcript. However, I added in my own reflections throughout the analysis in reflection boxes', these consist of feelings and personal thoughts. At this stage I also drew out characters and emotional hot spots as suggested by Gilligan and linked these back to the major themes whilst analysing them.

Step 2, the I poem: During this stage, the participant was put at the centre; all of the comments made by the participant which begin with 'I' are listed in chronological order. Researchers suggest that this is a simple yet powerful and a way to remind the researcher how participants narrate their stories, how they '*speak about themselves before we speak of them*' (Brown and Gilligan, 1992: 27–8). Creating an 'I' poem highlighted the relational and the temporal aspects of the narrative, as well as displaying the participant's own understanding of how they fit into a particular story. I could see emerging from the I-poems a narrative of their identities, and this gave insight into who they believe they are. I categorised these into 'stanza' that developed naturally from the flow of the conversation. I analysed each I poem excluding and including the major themes which presented.

Step 3: 'Listening for contrapuntal voices': I listened to and read the transcripts to determine what was unsaid or omitted from the story and considered why that may be. This is termed the 'contrapuntal voice'. According to Corby et al (2018) this allows consideration of what the participants have not said. Booth and Booth (1996) suggest that hearing what is not said can often be as noteworthy as what has been said. I listened for any power relations and dominant discourses that framed their narratives. I aimed in this section, to connect the personal with the structural by relating what was not said back to the analysis of major themes. The role of the researcher here is, '*retelling, remembering, and reconfiguring*' the story (Benhabib, 1999: pg. 348). The full detail of the analysis is provided in the next chapter.

3.7.2 Chapter summary

In summary, I carried out two interactional narrative interviews, the aim of which was to create a shared 'space' where the participants stories could be shared and facilitated. They were carried out from an emic/etic, critical social-constructionist positioning, drawing on influence from narrative and feminist theories detailed above. The narrative approach gave space for me to interact reciprocally with the participants and connect with them through my own stories and responses to their accounts. The LG guided me through the process and lead to the detailed analysis described in the following section.

Chapter 4: Data Analysis

In this chapter the participants' narratives are analysed interpretatively with use of the Listening Guide (Gilligan, 2015). Each story is presented individually; narrative analysis is integrated with verbatim quotations from the interview transcripts. I have provided my reflections separately within reflection boxes. Each participant's story contains 3 parts; Part 1 includes a summary (the plot and landscape), major themes, characters, imagery and metaphors and finally, emotional hotspots. Part 2, includes an 'I' poem and analysis of this. Part 3 describes the 'contrapuntal voices' found within in each story.

4.1 Part 1: The Cockroach in the Cupboard: Alex's Story

4.1.1 The Plot and landscape

Alex is 27, has scoliosis and she grew up in outside of the UK and has lived here for 3 years. In her view, in her country of origin you are only considered disabled if in a wheel chair, blind or deaf. Her impairment meant wearing a back brace from ages 5-16. Alex clearly recalls having to undress for PE in a cupboard so that her back and her brace were not seen by her peers. Alex's mum referred to her teenage years as the '*cockroach phase*', she wore mostly black and became more insular. Alex spent 2 hours per day completing physiotherapy; she missed social times with peers as a result. She was significantly bullied in secondary and primary school due to her impairment. She coped with this through unhealthy and damaging self-deprecation; this was perceived by those around her as strength and grit. She hated her body and internalised the bully's comments. She thought nothing positive about herself and was jealous of a close friend. She didn't fit in. Alex was a flirt; she flirted overtly with boys as a teenager so that they'd find her attractive, she thought this was a way to compensate for her body and that her body needed to be compensated for.

When she entered a romantic relationship and lead to her valuing her body a little more, but perhaps only when it was validated as being attractive to a man. She described herself as lucky for finding this person. She can reflect on this now as being influenced by society and

the media, expectations in films and TV programs that women should be perfect physically and mentally. Regardless, she still finds it difficult to have her physical differences highlighted by her clothing or posture. Though now she acknowledges that she is disabled by definition, she rejects the terms through fear of stigma whilst highlighting the conflict of other people rejecting her as so. I have described this in transcription as being 'in limbo' not disabled enough, but not able enough either; essentially, 'not enough' to ascribe to either identity.

To follow is the analysis of Alex's story, drawing together of major and minor themes, characters, emotional hotspots and so on. Quotes are taken directly from the transcription; the numbers refer to each verbalisation made by both myself and the participant. The participant's contributions appear in bold for clarity (The full interview transcript for Alex can be found in Appendix 5).

4.1.2 Major Themes

Theme 1: Hiding

Alex made several references to hiding her impairment, hiding in clothes, hiding by avoiding social situations and being hidden by adults in her life. Firstly, though, it is interesting how she was hidden even by the values held in her own culture, as follows:

84. ***Cause the word disabled wasn't even mentioned. Ever. First of all I think because there wasn't the possibility of mentioning it because the laws in 'my country' about disability are quite, more strict about disability than they are in England***

85. *Yeah*

86. ***You need to be in a wheelchair you need to be blind or deaf to be considered disabled***

This is an interesting intersection of disability and culture, the way in which societal and legal definitions effectively prevented Alex from identifying as disabled. It wasn't 'possible'. She had been prevented from entering disability culture from the beginning. However, as we can see below she was not considered able-bodied either, or treated as such. I wondered what this meant for her connectedness to her culture and where she 'fitted in'.

On a social interactional level, the most emotive descriptions Alex gives of hiding can be seen in the following interaction:

127. So like those type of things and my mum was really good at that cause she was the one buying clothes when I was a teenager and she would always buy the clothes that would make it less obvious

128. *That's interesting in itself isn't it...?*

129. Yeah 'cause I had to hide it, I had to hide it

130. *Yeah*

131. And I...I still feel like that to this day I think

Alex said that she 'had to hide it' in such a final and desperate tone it reflected to me her desperation at the time to not be seen and essentially, to be able. It sounded almost life or death but like a decision that was not hers to make. As stated, it was of interest that Alex's mother reinforced this and how this was appreciated by Alex at the time. Yet juxtaposed, her mother enabling her to hide reinforced the idea that she should.

271. Nowadays, if someone made me do that now, I'd say fuck you

272. *Of course! Why would I do that, I'd rather be comfortable and have a different back! But that's not...*

273. Cause actually it didn't help, so it was for nothing I fucked my childhood and it ended up the same

274. *It comes back to that normality you mentioned*

275. Yeah course my parents wanted my back to be normal

Being hidden by her school (in the cupboard, which influenced the title of her story) seemed an important feature of Alex's hiding story. She speaks of this in disbelief and detachment as if describing someone else's life:

57. Not because of adults because I never had any adult support what so ever, none, like I – it was very much like, it wasn't talked about it wasn't, I don't want to say I was a pariah because I didn't feel like that as a child but now thinking back to way the adults treated me was very much like a hush hush type of thing – cause I had to wear the corset for 24 hours a day but for example if I was doing PE I was allowed to take it off and then have to put it back, so I would do that in like a cupboard, like where they kept the brooms and the...

Being disabled was not in the discourse or narrative of those close to Alex in her adolescence, it was not talked about, it was 'hush hush' and therefore wasn't 'a thing' as she describes later. This interaction provides a stark description of how adults in Alex's life tried to normalise her through their 'nothing to see here' approach. As this was carried out by educators, we can perhaps assume that this was carried out with Alex's interests in mind. Contrastingly the effects of this were clearly longstanding and harmful for her. Furthermore she did not recognise this taking place when she was a child, it is reflecting on this that has allowed her to evaluate it as potentially damaging. This suggests to me that Alex, at this time did not have an input in her own support within school, she had no voice. And again further into the interview Alex explains:

68. *That's difficult*

69. ***It's hard***

70. *sounds difficult;*

71. ***So it was very much like yes here you go into the cupboard get changed and come back out, it was like nobody wants to see you, acknowledge that its even...***

72. *Yeah*

73. ***... a thing...I dunno***

Here, Alex deconstructs what happened to her and brings to the surface the subliminal messages she received when this took place. In this evaluation of her own story, what began as an almost comical and caricatured description of an event that neither of us could quite believe had happened, Alex's description become serious and flat. In her final words on the matter, I could hear that this was painful for her to describe. It became clear to me how

adults hiding Alex, likely perpetuated her need to hide. This seems to be a story of the internalisation of these messages.

Reflection 1: Here I felt a significant anger and frustration towards the adults that had reinforced Alex to hide her impairment and in turn, caused her to feel this way. This resonated with me and triggered memories of events in my own adolescence in which I have been 'hidden' such as being forced to work in one classroom 1:1 for 3 months whilst recovering from surgery. I empathised with Alex, her physical needs did not come into this story, the reason she was encouraged to change in this way was for others' feeling. Alex's wellbeing and her identity were not considered by the adults in her life. How could adults not reflect on their practice in this way? For me, this denotes a lack of empathy and understanding of disability that I observe at times in my own practice. It made me realise the strength of mainstream narratives around disability and the dehumanisation we suffer as a result of those.

The response of her peers to her impairment, which was largely negative and described by Alex as bullying as follows:

44. *What was your experience, how do you feel you were viewed by others? In adolescence?*

45. ***Like a weirdo I suppose, I got bullied a lot in school in general, especially that one, it changed a lot when I went to the A level school – causes it was a bigger school, nobody really knew me, like only my classmates, but they were more focused on other things I suppose***

We can see here that so far in the story the subliminal and explicit messages Alex is receiving socially, from adults and peers are negative. I wonder how much being hidden by adults perpetuated the 'different' and 'weirdo' stereotype held by her peers. I found it interesting in terms of her identity that a change in her story, a move of schools, seemed to have given her a fresh start. It is interesting that Alex chooses to reason this around changes to the people, school size and their interests; all external factors. For me, it highlights how much this mattered to her and how much the perception of others mattered to her at the time. Again she references hiding as she explained that her new peers were 'focused on other things'.

Here she described how much easier it was to hide, this time in plain sight, in her new school.

49. And I couldn't do it in the smaller school because it didn't have them and when I moved I realised that I could, I was not so much focused on it if that makes sense, because like it was a big school I could go to the like, for example, one thing that was very hard in the small school was going to the playground like normally during lunch times and break times I would stay in class or I would kind of hide – sounds awful but it's true

50. Ok

51. Because being in the playground is when everybody sees you and people will normally being playing football and things like that and I, I couldn't move very well you see

Alex expresses relief at being in the new larger school so she can effect hide more easily; she describes her classmates as being focused in other things. This presents a very high level of self-consciousness. It is interesting how Alex references her impairment as a reason not to play with peers but only after noting that 'everyone could see her' I perceive this to be her placing the social aspect of being disabled before the physical aspect in terms of importance.

Alex also described hiding through 'compensating' for her impairment through her interactions in early romantic relationships as an adolescent.

137. Yeah and even with romantic relationships, I remember I was this is going to sound really bad on the recording but I was a little bit of a slut...

138. Ha-ha...

139. Not sexually mind you

140. A flirt maybe?

141. Yeah

142. Yeah

143. Ah because I think I was so looking to compensate for how I view myself as disgusting that's not worthy of ever having a partner cause who is gonna want me naked like

144. ... I did different to you I completely hid, well like they won't fancy me anyway so just cut that out as an option for me there was a – I now, reflecting I put that down to lack of role model, personally like

145. Hm yeah...Pffff. Where do you see woman with a physical disability being like lusted after?

147. No. No you don't now!

148. Are we joking? Ha-ha

Here we can see Alex identify strong negative feelings towards herself such as 'unworthy' of having a partner, we can see the influence of being dehumanised in school, being hidden by adults and how this negative view of herself leaked into other aspects of her personal life, such as in forming relationships. She used a different 'persona' in order to compensate for her impairment, she had internalised the idea that she was not attractive or enough.

Reflection 2: Together we made the connection of our dissatisfaction with our disabled bodies and the lack of disabled role models. I was referring role models on a personal level; it is interesting how Alex extended the point to refer to a wider context. This is not something I had considered, it was a moment of sharing knowledge and observations which connected us.

In this space she, nor I, seem to feel the need to hide at all. It is clear above, where the tone and mood changes from sadness at reflecting on the dislike we felt for ourselves to humour and sarcasm in recognising the potential route course of this. Perhaps our humour was used to help us both heel through the process of this interaction.

We can see the multiple levels in Alex's hiding story; from societal to collective, to individual and personal. She is initially hidden by not being afforded a place in the disabled community by her culture. She is physically hidden by her teachers, she is not acknowledged by her teachers as in need of support. She is hush-hushed. She is hidden by her parents and encouraged to hide by her peer's negative interactions. She even hides behind exaggerated versions of her own constructs. She seems to assimilate this and looks for hiding places as she moves onto the next phase of her education and adolescence. She isolates herself because she has been ostracised by others. Finally she explains that she continues to hide her body.

The fact that Alex has carried these feelings of needing to hide into adulthood may suggest that for her there may have been a large emotional impact of the 'hiding' on her disability identity and how she views her body/impairment.

Reflection 3: Being able to discuss being hidden in this way by adults was cathartic for me and it was powerful to be able to speak frankly to Alex about this. The sharing aspect was positive for me and I think it may have been for Alex; however, acknowledging how these events had affected Alex into adulthood was upsetting and thought provoking. It made me reflect on how I interact with young people in my role as Trainee EP. It made me reflect on the practice I see from educators and whether I can intervene in some way to ensure that children are not 'hidden' as Alex was.

Theme 2: The middle ground

There is a story perpetuated by both her culture and the lack of acknowledgement of her impairment that Alex experienced and this left her in 'limbo'. Her cultural and societal background depicts disability as reduced to a small number and in extremes:

84. ***Cause the word disabled wasn't even mentioned. Ever. First of all I think because there wasn't the possibility of mentioning it because the laws in 'my country' about disability are quite, more strict about disability than they are in England***

85. *Yeah*

86. ***You need to be in a wheelchair you need to be blind or deaf to be considered disabled***

There was a societal blockade to Alex identifying as disabled, in her culture a medical and legal definition had a powerful role to play. The option of having a disability identity was therefore taken from her at an early age. There is no option to have a choice within this model.

Alex goes on to say:

89. *Yeah, that's interesting because what does that mean in terms of like feeling valid, for example... it's interesting I just wonder what that would mean for your identity if you are not valid as a disabled person but also...*

90. ***You are not normal either***

91. *You are living a disabled life...so to speak*

92. *Yeah, yeah I think it's that middle ground of you know you are different but you're not different enough to get like help, if that makes sense*

Hence, I have chosen to describe this situation as limbo. She's not able enough, she's not disabled enough to count as a member of either community and neither forms a large part of her identity. This highlights a story of being valid to some degree.

Alex highlighted to me the influence of the media, particularly which is targeted towards women, we discuss this in depth at point 179. In this discussion Alex makes the following statement:

196. *Yeah*

197. *For me it is different, for me I looked like a model, very fit*

198. *You had that experience of having the 'perfect body'...*

199. *Yeah and still being thought as disgusting, because of my impairment*

This again shows her being in limbo, she had a strong and slim body, the desirable body at the time, a very 'able bodied', but it did not count. This still did not afford her the privilege of being accepted within her peer group as an adolescent.

Contrastingly, some of the mixed views Alex has around identifying seems to arise from her rejection of the term disability, which seems a form of self-preservation, as seen here when discussing aging:

301.... people tend to go 'oh but you'll be fine look how you cope with it now' – but I'm 28! My parents and friends have said things like that, it's like 'how do you know? I might not!' I had friends say 'you're not really disabled are you..?'

302. *Well are you surprised I didn't identify with it, people say that stuff all the time*

The feeling of displacement she experienced in her adolescence seems to have been carried with her into adulthood. I wondered if this statement was a true reflection of her feelings or more an acceptance of her not being 'allowed' to belong.

In sum, certain events in her story narrated her life more into the accepted 'able' community such as meeting her long term partner, attending sixth form and being hidden. Coming to the UK with its differing culture seemed to allow her to identify with the disability culture more. Alex sights meeting with me as a turning point that allowed her to engage in more discussions regarding disability and being a disabled woman.

295. *Last question is: how have you found sharing experienced with a disabled woman?*

296. ***I think it has been amazing, when I met you it has helped me think way more about things I never thought about that are important e.g. earlier, never complaining or questioning, no acknowledgement that I'm disabled, until I met you and we started talking about it***

For me, this goes some way to showing that this shared experience was powerful and liberating for Alex. Alongside sharing experiences with other disabled women in informal settings, engaging in research has been a powerful experience for her.

Reflection 4: I felt a combination of relief and humility when Alex responded to this question. That is relief that the process had been helpful for her and not challenging. It felt very powerful to be able to bring these ideas to her attention and to help her process them through narrating her story

Theme 3: Game changers: Turning points towards a disability identity

The following three stories within Alex's interview show turning points in the way that she viewed herself. In contrast to the other themes, she changes the way in which she identified/s as a disabled woman, the story becomes one of realisation and positivity. All three stories describe an interaction with others that supported her to feel valid, accepted and useful; in my view they helped her to reframe her view of herself and her impairment.

288. ***I think that matter of fact thing works really well, my fondest memories of my mum and helped a lot was – I was going to the beach and had a bikini and my back was on show and I didn't want to wear it getting upset etc. and my mum took me, put me in front of a mirror, she was like look at it, this is your body, you get one, if we can fix it we will, if not it's your body is it going to stop you from getting on with your life? If it is that is stupid. She was so matter of fact but it really helped me***

289. *It is validation?*

290. *Yes and that fact that there are things that you cannot change in the world and yeah, you have the short straw in this society cause you're not seen as normal, but who the fuck cares, nobody's bothered and no one is going to help you if you don't help yourself I think*

I felt that this was such a key turning point for Alex in her story I could almost hear her Mum's definite and pragmatic approach through Alex's expression. Her reference to 'drawing the short straw' was revealing. This, for me, suggested that her struggle in seeing the positives in herself such as resilient and strong; I wondered if this was actually acceptance of a 'fate' rather than acceptance of her impairment and disability status in a positive sense.

Reflection 5: A sense of unfairness is definitely something I grappled with in adolescence and is something that is important to acknowledge. This passage made me think of times when my feelings such as this have been dismissed by others (friends and family), and what a difficult balance it must be to support a child with those feelings if you are a parent. I was also reminded of interactions I have had with people who have validated my disability identity, from my parents and a teacher, and how these interactions strengthened the relationships. However, I found her reference to 'drawing the short straw' challenging to hear.

The second story of this nature; begins with Alex being offered considerably extensive back surgery in order to 'correct' her spine at the age of 15. The surgery was fully for cosmetic purposes and could, in fact, reduce her movement making her less able. By consent, I am referring to Alex consenting to have the surgery.

281. *I hated it; I wanted to change it, absolutely*

282. *But yet you didn't consent...?*

283. *I was this close, you know what stopped me, it would've fused my lower and upper back completely – no bending or twisting of the torso, that's severely impacted – what made me not was looking online for I found a dancer with scoliosis, had the op at 20 and because of it she couldn't dance and she ended up reversing it at 30 something, and that this was the best decision she made; accepting her back and her movement and not wanting to change it*

284. *Did that impact you in any other way?*

285. I suppose it did help me to think well it's my back and feel ok about it not embarrassed...I'm not saying I felt 100% with it at that age but looking back it really did start the path..

This story stands out as not only a story of acceptance but the first story Alex tells where she voiced her wishes and took control over the decisions made about her own body as an adolescent. I saw this as a very powerful moment in Alex's development, where she put a stop to others trying to fix her and therefore she began to 'own' her own body. I understand this as a small story of personal triumph over the able bodied narrative which had been forced upon her by her parents, peers and culture. By doing so she was empowered and changed her story going forward, from one of idealising being able to one of acceptance of the disabled self. Furthermore, it highlights the potentially life changing impact that shared experience and stories of impairment had in Alex's adolescent life. These seemed to be discovered through her own research, further evidencing a story of taking ownership in this piece.

Reflection 6: I found Alex's reference to 'hating' her body upsetting; in empathy for her feel such strong negative emotions about herself and secondly in reflecting on my own experiences of having similar feelings towards my body.

This part of Alex's story made me frustrated by the lack of representation and anger at the idea that life changing decisions can be left down to chance. I felt a sense of connection with her around having to face such large decisions at a young age having consented to corrective surgery at age 13.

Theme 4: Finding a connection

Elements within Alex's story which show her looking for connections, early on in this story, where she refers to her flirtatious nature in her adolescence and her inability to connect with others, she seemed to be making efforts to build connection. She also refers to her struggles with keeping friends. She is now looking for connection through her work as we can see below and finally by engaging in the study she has successfully connected with someone she perceives as similar, with similar experiences.

Here, Alex is discussing her beliefs around why she has chosen her career working with children who have special educational needs and disabilities.

210. *I dunno if you have that if you come across someone else with an impairment or? Cause I feel they're 'like me'....*

211. *Well I think it's one of the reasons I wanted to work with children with SEN because my life in school was hell, was horrible, not only cause of my back but also I had difficulties reading and writing but my back was also very obvious and that's one of the things that, I don't want people to go through the same thing and I suppose that's why – yeah I do I get, when I work with children I think 'I know where you're coming from'*

212. *Yeah you feel like saying that to everyone – I know what it's like to be the one that's pulled out of class, missing lessons cause you've got this and that appointment, looked at talked about catered for all the time...*

Reflection 7: it was interesting how Alex has used her 'horrific' experiences, which could be termed traumatic, it certainly sounded so. She seems to have harnessed the negative feelings she experienced and used them to propel her career. It felt empowering to hear and for me showed courage in facing this, as it would be understandable for someone to avoid the environment that they had found so negative.

There is a sense of looking for connection for her but also of providing connection and a relational experience of the children that she is working with. She displays considerable empathy and this seems as if it is a way of coping with her own traumatic experience of school. This could show the importance of creating shared spaces and the importance of sharing our stories through our work, for both parties.

294. *Last question is how have you, found sharing experienced with a disabled woman?*

295. *I think it has been amazing, when I met you it has helped me think way more about things I never thought about that are important e.g. earlier, never complaining or questioning, no acknowledgement that I'm disabled, until I met you and we started talking about it*

296. *It's a long time isn't it, 26 years to be like, no actually it is quite difficult, as much as I want to be very feminist and pro-disability and say we can do anything! It is*

harder, life's harder but that's ok because other things in life are ok, good profession etc.

297. For me especially, the acknowledgement and the anxieties you had growing up for example having children, I never spoke about that with my mum ever, yeah or talking about being old and what happens if I get worse all these things

Acknowledgement and being heard seemed pertinent here, as well as having someone to speak with who understands your situation. It seems that engaging in the research process has allowed Alex to have a different perspective on her impairment and to be able to reflect on what she has experienced in her adolescence.

Reflection 8: I found it incredibly positive and affirming that Alex found the process helped contain and affirm her anxieties, by her ability to share with me. From her past experiences to her future worries, I felt it had been cathartic for her and had connected us further.

4.1.3 Characters: Saviours and Influencers

The characters in Alex's story seem dichotomous. Alex's mum features heavily in the story; her influence is prominent in the themes detailed above and she was seemingly the most important character in Alex's story of adolescence. She provided her with affirmation, clarity and pragmatism. Contrastingly both of her parents are referred to when Alex discusses her impairment not being acknowledged, which is an interesting feature in her story in terms of receiving conflicting messages about what it meant to be disabled.

It is interesting that Alex seems to have what could be described as 'saviours' (such as her mother and her partner, Ben) and 'influencers' (the dancer, the friend, myself, peers, children with SEND and her teachers). The influencers are positive, all bar the teachers and peers; however they still influenced the way she viewed herself. This raises two points for; the relations in Alex's story are key factor in her self-worth and self-concept and secondly, she is missing from her own story. In this, I mean that Alex doesn't tend to attribute her strengths and the positives in her story to her internal traits; her ability to cope and her own resilience. From my stance as narrator I can observe that these traits are here and I perceive her as an empowered and strong character who is not willing to accept passively the barriers that have been put up for her.

It seems that Alex didn't recognise these traits herself and possibly may not now, she is telling the story but in my view overlooks herself as being 'influential' or a 'saviour' to herself. In my view, this is likely due to the negative representations of disability she has witnessed and the lack of acknowledgement she received throughout her teens.

Disabled peers are also missing from her story; specifically there are no other characters with Scoliosis within her story that are closely linked with her such as friends or family. Alex identifies this for herself in this passage:

299. *Exactly or there had been adult role models, teacher, TAs and even now I don't know anyone that has scoliosis and is like 50, are they ok?! Are they, how's things? It sounds silly but it's always at the back of your mind, a constant, if I talk about things with my boyfriend, he's useless, if it's about my worries about this he freezes – he can't relate*

4.1.4 Imagery and metaphors

The imagery used in Alex's story shows considerable juxtaposition. She makes dark references such as to her 'cockroach phase', but recalls this with humour. She described her school life as 'absolute hell' on more than one occasion, conveying a strong emotional response and a very clear memory of the negative responses and thoughts towards herself that she carried. There is an undertone of suffering and difficulty. I found a certain irony in that these feelings had a social cause (bullying, exclusion) whereas her body, which caused her a physical pain, was described in a powerful and positive way. In opposition, her body is referred to as 'pro athlete, super strong and twig/tiny' (this being a desirable physical appearance at the time). These metaphors, I feel, help Alex portray the conflict of these factors in her adolescence and the frustration of almost having the normative desired body, almost being able.

When we discussed how she felt in school, Alex explained that she felt 'like a weirdo' she describes how her impairment was 'hush hush' as I have explored above in theme one 'Hiding'. But most powerfully for me, Alex claimed that 'I don't want to say I was a pariah'; the first part of the sentence maybe suggests that Alex knows that this was how she was treated but she cannot emotionally face this or that she wishes to soften her true reflection on this due to her pragmatic approach to disability. The term Pariah provided powerful imagery of the level of social exclusion Alex experienced an adolescent. The comment

shows further juxtaposition; it is soft '*I don't want to*' and then harsh and dramatic in the term '*Pariah*'.

Reflection 9: To ensure I captured Alex's meaning in her I searched the term Pariah and the following definition was provided:

Pariah

1. an outcast.

"they were treated as social pariahs"

synonyms: outcast, persona non

grata, leper, reject, untouchable, undesirable;

rare unperson

"they were treated as social pariahs"

It's synonyms struck me, particularly '*unperson*' '*reject*' and '*leper*'; the feeling of rejection Alex faced in school sounded dehumanising for her and in listening to her discuss this gave weight to the literature I have read regarding dehumanisation of disabled people. It added a realness to this that proved both upsetting and frustrating that we, as disabled people have to experience this. This feels like the ultimate exclusion for her. Yet the way she says it unapologetically made me think she was trying to make the situation less unbearable – I wasn't sure if that was for my benefit or her own.

4.1.5 Emotional hotspots

As the topic is emotive, and my experience means I am very emotionally close to the text, there were several emotional hotspots. These were times when Alex was particularly emotionally expressive and in turn where I was most emotionally affected by the interview. These tended to be depictive of negative emotions in Alex's story. Simply asking about her teenage years brought about the response of an expulsion of air in a 'BRRRRRRRRRRRR' depicting a turbulent or even 'cold' story of difficulty was about to begin. Anger and contempt feature also within her story she states: '*well fuck you Alex*' and '*I hated it I wanted to change it absolutely*'. Her language is aggressive and strong, depicting her strong emotions about her experience and how they have affected her.

Most emotive for me, and likely for Alex, is when she expresses the feeling that she '*fucked her childhood*'. It sounded as if it hurt to say and it was painful to hear. It is interesting that she takes ownership of this also. It made me think that the strong emotive impact meant that

this was a feeling that was unresolved; it was said regretfully and with resentment as if Alex was grieving this time period.

Following this, when discussing her shared experience with me as part of this research, Alex explained that:

296. *I think it has been amazing, when I met you it has helped me think way more about things I never thought about that are important e.g. earlier, never complaining or questioning, no acknowledgement that I'm disabled, until I met you and we started talking about it*

297. it's a long time isn't it, 26 years to be like, no actually it is quite difficult, as much as I want to be very feminist and pro-disability and say 'we can do anything!' It is harder, life's harder but that's ok because other things in life are ok, good profession etc.

298. *For me especially, the acknowledgement and the anxieties you had growing up for example having children, I never spoke about that with my mum ever, yeah or talking about being old and what happens if I get worse all these things...*

There was a shift in tone here from one of difficulty and pragmatic acceptance of her disability, to relief. This was said on an outward breath, both her voice and her body language changed in response to the change in topic. There was a sense of connectedness and Alex spoke freely about not having identified before coming to the UK and meeting myself. For me, this interaction goes some way to show the importance of sharing amongst others whom identify as disabled. This feels like a story of affirmation and reassurance, both of which can be found in those who share some of your experiences.

4.2 Part Two: Alex's I Poem

Alex's complete I poem is provided in Appendix 6. The 'I' statements were taken directly from the transcription of my interview with Alex. They remain in the order in which they were shared with me. I have provided subtitles to create stanzas. This is to help guide the reader and provide a context to the statements; these are placed where there were changes in direction in our dialogue. There are of course variations in each stanza but what appears throughout the I poem, are the instances of others 'doing to'. From what she had to wear,

where she was, who she was exposed to even through to how she was as a person, with the assumption that she is resilient in stanza 9:

Reflecting back on bullying

I remember for me with the bullying

I was outspoken

I spoke back and it looked like I was defending myself

I was (a victim)

I would stick up for myself

I'd say 'yes I know, I know don't you see, do you want to touch?'

I would

I wouldn't feel bad about it

I wouldn't internalise what they said as I teen I did

I would snap back

I was commended for that

I was able to snap back

I used were self-deprecating

I would internalise but it wasn't seen like that

I don't think it's about pity

I totally disagree

I think it's about recognition

I was put in a cupboard, cause people didn't want to look at me

I interpret this as, even her autonomy to have particular personality constructs was taken from her by adults with good intentions. The only way to challenge this was defiance and

feistiness, putting her in a rather lonely position of having the responsibility over challenging stereotypes and assumption of the able bodied characters in her story.

What strikes me in Alex's 'I Poem' is that there are no instances of 'I am' throughout the piece. This is of most interest within stanza 12:

Being disabled now

I think there are two things to this

I probably don't (identify)

I don't because of the perception I still have in my head

I think rationally

I would be classified

I'd say no it was never discussed until I came here (UK)

I don't like discussing or talking about

I know I'll be worse with age

I may need a chair

I'd probably be considered disabled

We can see the use of '*probably*' and '*would*', '*considered*', '*I think*'. Nothing is concrete in her identification; there are no proclamations of 'I am disabled'. There are also no 'I am' statements to refer to her constructs and her beliefs about herself now. Naturally the majority of the interview involves reflecting, so this may not be expected but for the latter part of our conversation, there are still no definite statements. This gives me the impression that Alex may still be on her way to accepting her disability and appreciating her body and her positive character traits. I wondered if my earlier point of having her autonomy removed interacted with this lack of expression of what and who she is. By this I mean that she rarely situates herself in the present, or speaks in present terms, and that this may say something about her uncertainty or reluctance to identify as disabled.

4.3 Part Three: Alex's Contrapuntal Voice's

For context, '*contrapuntal listenings*' ensure that the researcher can pay attention to the numerous ways in which participants tell of their relationships (Brown & Gilligan, 1992). The third and fourth listenings are intentionally aimed at giving the researcher chances to highlight perceptions into how the participant '*attends to his or her life, as a way of knowing or as a channel of discovery*' (Woodcock, 2010). An important factor of these two listening's '*is to extract two themes of the narrative that melodiously react with one another or that are in tension with each other*' (Raider-Roth, 2000, p. 50 In: Woodcock, 2010).

There is an interaction between the key themes of '*Hiding*' and '*Game changers*', facilitated by the characters in her story, Alex is gradually able to come out of hiding through getting closer to her disability identity. She does this through her relationships with her influencers. In other words, the more positive messages and affirmations she has the more accepting she is of her own body. However, the two themes also contradict one another in that Alex still does not fully identify as disabled due to, as she describes, the stigma and the responses of others. This, to me shows how her personal development is hindered by cultural and societal pressures. It is interesting though that she highlights a change of culture as a positive in identifying as disabled.

I feel that there are many voices in Alex's story; ones of defiance, anger, and acceptance of what she has experience. However, there is a voice of forgiveness that I believe is missing and a voice of acceptance of herself and her body. As Alex narrates her story from adolescence into adulthood, it does not seem that she has forgiven herself or her body for the difficulties she has experienced, despite her awareness of the contributing factors of society and culture. There are not many instances in which she refers to herself positively or as emotionally strong, yet we would assume this given how she has shaped her career based on her experiences, that she is. On the other hand, this could simply be that her approach and outlook is pragmatic and that in itself is her way of accepting herself. She is matter of fact. Although, there is also a lack of forgiveness towards her peers and teachers at school and this possible resentment is being used to fuel her determination to make a change to the system that let her down. What she knows about her experiences is that it was 'wrong' and what she knows about herself now is that her experience can help to make things 'right' for others.

I feel that these facts in Alex's mind give her power to challenge other and empower her to not accept what she accepted during her adolescence. Forgiveness only really appears in

Alex's story at the very end, it forms the final line of her 'I' poem: *'I think we are very much allowed to complain'*. But notice she refers to us both. I wonder if Alex needed this shared experience and to share her trauma in order to essentially come to peace in some way with the challenges she has faced (physical but predominantly social challenges). Perhaps it is easier for her to tell me, and affirm my feelings alongside her own, this is safe, it allows her to acknowledge her pain in a safe way, and it's less personal. Overall, Alex portrays a powerful and pragmatic story of her disability identify in adolescence and into her adult life and career.

4.4 Part 1: The technical Amputee – Sarah's story

4.4.1 The plot and landscape

Sarah is 25 and is completing her PhD at a university in the UK. She has a limb difference (partial amputation of her foot) and is also diagnosed with Autism and Dyspraxia. The latter diagnoses came in early adulthood. She attended a private school in her adolescence, an all-girls school. She experienced bullying here. At 14 she had surgery on her foot, she needed crutches. She sites this as a trigger to some difficult thoughts about herself. As she moved into sixth form and out of secondary education it sounded as though she gained confidence. As she developed into an adult, she gained diagnoses of Autism and Dyspraxia; this allowed her to make sense of her adolescence to some degree.

Sarah's story feels varied and she speaks in a way that sounds like she is figuring out where she stands as she speaks with me, there is something very 'present' about her account. I could sense a lack of clarity for her and a lack of understanding of where she fits within the abled and disabled worlds. She seems to have only been moved towards a disability identity by pragmatic experiences in her life such as being diagnosed and being awarded Personal Independence Payment (PIP). As you will see from Sarah's I poem, she often phrases statements as 'I suppose' or 'I think' depicting a level of uncertainty. I picture her in a vast landscape with a multitude of options and possible groups to belong to and the pressure of all of them looming over her, with judgemental on-lookers ready to remind her of her privilege as soon as she tried to enter the disabled community. These seem to exist outside and inside of her personal narrative. The full transcription of Sarah's interview can be found in Appendix 7.

4.4.2 Major Themes

Theme 1: Lost in the intersections: Class, Gender and Disability

Throughout the interview Sarah made many references to not quite fitting in and claiming multiple identities through being raised in a, as she terms, privileged environment to a middle class family but ascribing to a disabled identity that she perceives as being very juxtaposed to privilege. Along with this come pressures to hold up expectations and worries about 'counting'.

Here Sarah describes her impairment:

- 1. Would you like to start by telling me a little about your disability? Or any stories that come to mind*
- 2. Yeah my disability is probably at the mild end so, I was born with my left foot deformed and so that sort of my toes were pointing the wrong way so I had surgery when I was really small and then surgery when I was 14 so I suppose, it's not a named disability but it effects my gait and how I walk and pain etc. and I'm also dyspraxia so that doesn't help but I think it is my whole left side, to some degree, it's not got a name***

This interaction is taken from the very beginning of the interview and we can see Sarah struggle to identify what her impairment is and means for her; it is almost as if she finds it hard to justify being disabled and this is the first time we see her struggling with identifying with one area of her life.

Reflection 10: In this interaction I felt that my question was 'safe' it was none specific and opened up the conversation. However it felt as if Sarah's response went very quickly from explanatory to justification and I could feel a tension there in her trying to explain something that didn't have a clear definition. This also showed to me the importance of leaving the questions open, this allowed Sarah to interpret the question and convey her own meaning and feeling towards it.

Further into the interview, Sarah describes events in her life which have drawn her closer to a disability identity but that also seem to have caused her confusion around whether or not to identify.

3. *Has there been a significant point where you reframed your view of being disabled?*

4. ***I think getting the other diagnosis and applying for PIP has made me view myself differently because I've got quite a high, well highest care and normal mobility I suppose in my head I'm like well if I've got that then there clearly is something that's a bit different even if I sometimes I think of its mild and I dunno if that's cause of other people going oh it's not that bad etc. so I suppose I think that's reframed it in my mind sort of but then a physio said to me the other week, well you wouldn't could yourself as physically disabled would you and I was a bit like, hmmmmm ...so I don't know I think its cause I can hide it quite easily where as if I was a wheelchair user you can't hide it but in most situations I can hide it so it's almost like an invisible physical disability that doesn't really exist in the world***

This short interaction is filled with complexity, the receipt of PIP almost gave permission to Sarah to identify, she had a definite, an evidence base. She is disabled. However, a comment from a physio in more recent times questioned her status and this disrupted her identification again. There is a tension and to-ing and fro-ing caused by others in her environment, these interactions seem to impact Sarah and cause her to question herself. It suggests she is not secure in this identity in her own mind but also shows the great impact external societal influences can have on someone's identification.

Reflection 11: This interaction really resonated with me, I felt a connection with my own story, having a specific diagnosis but looking 'normal' yet, in one specific interaction with a physiotherapist in which my parents were told 'at least she's not in a wheel chair' and a comment from a friend that 'you're not really disabled though are you'. I empathised with Sarah, and felt her frustration at having to field the opinions of others, professional and informal opinions that others, generally, do not have to be subjected to on such a level.

Following this, Sarah links her disability status with her class status in the following revealing interaction:

116. The notion that disabled people maybe can't work or? Can't ...that sort of rhetoric

117. **Yeah and that I might be able to, as a disabled person, with my parents back ground I might not be able to keep that going – keep it up because I'm**

disabled, even though there's the expectation that I will do XYZ and in secondary school I think I did feel that as well because mum was like don't talk about money and we were not like obviously there was a massive range and we were nowhere near the top, people had new cars and it was awful... but it was still felt a clash even at that age of things

118. Sounds like a story about guilt?

119. There's definitely guilt there...yeah

She describes it herself as a clash, and one that she was made aware of from a young age. The pressure of keeping up 'middle class' familial expectations so to speak put an additional pressure on Sarah in relation to her disability status. It is interesting here that she clearly identifies herself as disabled. We can see the emotional impact of these two clashing social expectations. Neither of them sounds a safe or secure option for her and she is left in the middle.

Reflection 12: Here I had to reflect on my own, lack of consideration of this factor and the factor of class' impact on the disability experience at all. I am from a working class background and this additional pressure of maintaining and meeting expectations does not exist for me in the same way as it does for Sarah. This did however enable me to reflect on whether my socio-economic back ground (more so that of my parents) has impacted my disability identity, something that I had not previously considered.

Below we find Sarah beginning to tease out why it might be that she finds being disabled and female difficult:

113. I suppose, but now I know about women being oppressed etc. that wasn't even talked about in school and they were going for women in science that was like the big topic at the time but nothing about oppression and that, feminism, now I find it quite difficult being a disabled woman

114. How so?

115. Well, it more just feels like I'm in several different minorities but then also like I'm white middle class, I'm also in lots of privileged positions so it also goes against each other and that...that is probably the biggest fraud I feel, my background private school and that, in that sense I'm not minoratised at all

116. I wouldn't say I am either

117. Which I kind of feel like it clashes completely with the whole disability notion

She describes how is both privileged and mineralised. This provides an interesting depiction of intersectionality of gender, class and disability. Where the previous interaction showed the relational aspects of this struggle, here we can see Sarah identify the societal ones. Both groups come with a set of assumptions about the people within them.

Reflection 13: Though I am of a different background to Sarah, I also feel this sense of a 'clash' as I would also consider myself as privileged due to my current circumstances, both professionally and personally. I felt a frustration here about having to feel the associated guilt based on the expectations of others. Both myself and Sarah seem to have a barrier in place to be able to accept and play out our privileges alongside being proud of our disability status.

We can see the impact of this upon Sarah in the passage below:

89. *So how has that influenced you now that time?*

90. *Erm...I would say I'm still quite anxious form my school experiences, I don't think I've yet gotten to grips with where I fit in within the sort of PD world which, I think hasn't helped from secondary school yeah I don't think I've quite...I don't know*

She identifies the sense of anxiety this created for her in adolescence and how this has remained with her. This possibly shows the long term impact that her adolescence experiences have had on her; this highlights to me the important need for support for young women with physical disabilities at this time. Perhaps support could have allayed some of her anxiety in school which could have impacted her in her adult life.

92. *To what degree have your experiences in adolescence influenced what you do now? Your PhD?*

93. *My 1st degree was in primary education but I didn't get QTS to become a teacher so I suppose my experience was that, I...like being quite interested in inclusion and disability and like my PhD is on Autism in higher education I suppose, my own experiences have definitely influenced how I perceive things, I feel I'm quite open, whereas I don't think society necessarily is sometimes, so I think it's definitely shaped, what I do and think in that regard.*

94. *I think; I dunno if you're the same, but I wish I had had teaching around this in school*

95. **Yeah**

96. *It would've been helpful to hear those terms disability and inclusion etc. even feminism*

97. ***I didn't know about critical disability studies until I came here, like Autism as a social construct, and it's not necessarily that I agree with all the things its more, I hadn't appreciated that all these things exists***

There is the indication here that Sarah could have benefited from access to information and she makes the connection between simply having access to options, not necessarily being 'told', in her example regarding social constructionism and Autism. It seems as if the willingness to find out more about her identity and disability was powerful and influenced Sarah's career choices. I wondered if this said something about her need for an explanation and a place within the many intersections she is part of.

Overall in this theme, I felt Sarah gave a clear narrative of the challenges associated with societal assumptions, class and intersectionality within and between disabilities also.

Reflecting on the themes was a learning experience for me in terms of understanding class as an influencing factor within disability identity, showing the complexity of the disability experience but also the benefits to both parties in sharing this experience.

Theme 2: Feeling fraudulent

A very powerful piece of my interview with Sarah was when she referred to herself as feeling 'fraudulent' for claiming the status of disability.

154. ***I think in adolescence, we could buy anything like new shoes etc. if I needed them if its help my foot, they could, buy it and so I sort of, it almost feels like the monetary side of disability hasn't quite affected me and therefore it's definitely clashed cause then I'm like am I disabled am I not disabled then growing up that was defiantly a thing that conflict***

155. *In the literature there's a distinction between – you have an impairment but you're disabled by society but then we are not...just like comfortable background,*

normal but ...it's something about feeling valid again isn't it – but like I don't struggle but I also receive PIP and that makes me feel uneasy

156. I am very uneasy about that and well its more the piece of paper that I need but obviously I get the money as well, I almost feel like I'm not a stereotypically disabled person because at the moment I'm ok for money but the stereotype that you're not and you're not surviving

There is a story of conflict here around the societal meaning of disability and its association with being less able to work and be financially stable. It is interesting that here Sarah identifies that she does not fit the stereotype but then has perhaps internalised this and has potentially taken on feelings of blame relating to this aspect of being disabled. This highlights to me the power of stereotypes and their influence on how one might view them.

Reflection 14: Here it felt like I made a connection with Sarah, in some ways it felt like a risk to share my own feelings on this topic before Sarah had and it felt somewhat out of place in the interview at the time. However I felt the conversational style of the interview provided an element of 'safety' for Sarah to be able to share. When she responded there was a definite tone to her views on PIP.

Here we see Sarah grapple with how to express to me that she is disabled and how to describe herself.

14. It's interesting because as someone who has had that term attached, it was slightly different to me I had that term attached and rejected it completely – compared to then how do you feel about that term now?

15. Err well I suppose I don't actually have one, I feel a bit fraudulent, and because it's not well I don't know. I can walk basically but not masses I suppose, not on concrete. If you go to the Doctors they like 'hmmmm' or google it there's nothing, so technically I'm an amputee, but that's only, that's if I'm being very technical

I interpret from this that she links being “mildly disabled” with “not being fully disabled”. She uses caveats such as ‘I suppose’, ‘not masses’ and ‘technically’ perhaps to soften the delivery of her description. I wondered if this was for my benefit or for her own. In terms of how comfortable she was to identify or whether she was wary of judgement from me as a fellow disabled person.

Reflection 15: This interaction reminded me of times when I have amended or softened my own language to describe my impairment. I notice that I will say 'I'm disabled' to some and 'I have a problem with my arm' or variation of this to others, to 'soften' the delivery of that information. This can depend on audience but also on how comfortable I feel with the person. I wondered if part of Sarah's difficulty in describing her impairment was partly due to the dynamic of being interviewed by an unfamiliar person.

As I could sense a possible discomfort and dissatisfaction with how her disability identity had been influenced in her adolescence and in recent years, I wondered what would have improved this for her. I used a typical narrative question to establish this:

157. *So how would you have changed your experience? The typical magic wand question*

158. ***So I think I would have changed my parents view on what I had so mums a Doctor, that probably didn't help anything I think I'd probably yeah if they had told me, cause all the way through - it wasn't like it, it just was how it was – that was life end of and it still is in a way....but I suppose if I had then been comfortable and if I'd have known that it was a disability then I think that would've helped, I think in school there was no sort of, it might've been the school I was at, you learned about drugs, alcohol, etc. but there was nothing about disability what so ever***

159. *Same here, there was sexuality, race etc. as there should be but it was like disability had been left off the list*

160. ***Yeah nothing at all***

Reflection 16: It was frustrating to hear that this was also Sarah's experience. I reflected on how this transcended class, we had been excluded from both state and private education in this case. The idea that the message of 'you don't count, you don't matter' comes to young women with disabilities directly from the curriculum is fairly shocking when brought to the attention in this way.

Theme 3: Visible and invisible

Sarah has had times in her life when her impairment has been invisible to the point of her own teachers being unaware, to very visible at the times when she has needed crutches. It is interesting how her perspective on the obvious nature of her impairment have changed over time. The following excerpt reveals how Sarah felt about being visibly disabled in her adolescence:

5. *So I had that because my tendons were too tight, so if I fell id go straight over I couldn't catch myself, so I suppose I'd spent every PE lesson id fall over if I ran, id fall flat on my face, so I experienced a lot of bullying, I was quite pleased that it could be fixed I suppose, but then it was also quite strange, cause well I spent all of the summer holidays on crutches*

...

6. *Yeah but then I suppose I felt very self-conscious about it going back to school, I didn't use my crutches which probably didn't help but I was just so self-conscious about the whole thing*

It is interesting that her discomfort within being seen and seen to be different was at such a level that she chose not to use crutches in her recovery. This should be the weight of this feeling for her at the time. I wondered if things might have been different for Sarah if her peers and teachers knew her to be disabled before this point. I wondered whether it would have been easier for her if she identified before this point.

In the following interaction, Sarah makes the point that often PD as an invisible disability is not considered. To me, she says this as if she has been 'left out' of being in the group termed 'invisibly disabled' one that she ascribes through her other diagnoses:

164. *Yeah it's fascinating, it's something I really relate to – I don't walk differently its only when people notice my hands that they can tell and there's pros to that isn't there, where you can hide it*

165. *Hide it yeah*

166. *But I think there are cons around maybe counting, like you said in your email?*

167. *I suppose for me it's like dyslexia and dyspraxia and all those ones, which are invisible but when it comes to invisible PD no one counts them as*

invisible, and so I think that's also like going through adolescence like having surgery that's when I realised that I was definitely different and I didn't like that and then it's still slowly, it's taken 10 years and it's still like...

Being visible in her adolescence enabled Sarah to recognise her difference from others and she reflects on the dissatisfaction she faced regarding this. She also expresses the length of time it has taken her to be less dissatisfied with her body. She said this with frustration, almost as if she was still waiting for her acceptance of this to come to her.

Enmeshed in this developmental process for Sarah is the idea though the acceptance she has from others may have been easier to gain if she was more visibly disabled. This is made clear in this interaction:

168.... and ended up on crutches and they thought I had arthritic sepsis or something but it turned out it was just these insoles but while I was on crutches, going on the tram in (City has been redacted), people were instantly like, they gave up their seat and I always think well if I just got some crutches... cause I have a disability pass but I don't feel I can ask someone I can move from their seat cause and I really struggle on the tram to stand and I just like oh...and also I feel like I'd be quicker on crutches walking, when it's a really bad pain day, it's just like oh if I bought some crutches... would it make it all better or would it be easier if it was something more visible, or...

Reflection 17: This is something that I certainly related to, it reminded me of times, post-surgery where I have been more visible, in a wheel chair for example. Responses to me were certainly more empathetic; however I had to experience being stared at or having unwanted attention. Now, I often struggle with the act of asking for help or asking for reasonable adjustments or access because I too look 'able'. Being able to share this with Sarah was far more affirming for me than when I have shared this with able bodied friends or family. It was interesting to think we would both possibly choose more negative attention and visibility, than silent judgement or having to justify ourselves by 'coming out' time and time again.

This has been reinforced for her by others in her adolescent life, where her needs were not visible to staff and therefore not known about until she had surgery:

169. *Did you have any additional help at that age or?*

170. No nothing I think in PE, they didn't know anything until the surgery – they saw the scar and were like that's quite major surgery... I was like yeah ha-ha, they didn't know

171. I wonder who that rests with

I wondered what the impact for Sarah was in terms of importance; they didn't know about part of her, her impairment until it was obvious. This highlights that information had not been shared about her physical needs at the time; this must have reinforced her invisibility.

Reflection 18: I felt a real empathy for Sarah in this scenario, post-surgery (aged 14) I was asked about my surgeries in person by more than one teacher, out of interest in what had happened, what the surgery was for. There was no consideration of the associated trauma or emotional impact of this on me. And clearly there was no consideration of this for Sarah either. This feels like objectification to me and it's hard not to view it as lack of care, even not this feels wrong.

When provided with a 'magic wand' scenario Sarah also highlights a wish that her parents had made her PD more visible to her. In terms of naming and recognition:

105. So I think I would have changed my parents view on what I had so Mums a Doctor that probably didn't help anything. I think I'd probably yeah, if they had told me, cause all the way through it wasn't like it...it just was how it was – that was life end of and it still is in a way....but I suppose if I had then been comfortable and if I'd have known that it was a disability then I think that would've helped, I think in school there was no sort of, it might've been the school I was at, you learned about drugs alcohol, etc. but there was nothing about disability what so ever

Here we can see that not only was her disability invisible but disability as a concept was invisible to Sarah during her adolescence. She expresses how she could have been comfortable suggesting a discomfort she experienced at that time. It seems to have been a discomfort that could have been eased if her disability was made visible, in a figurative sense, by those around her. Again Sarah expresses herself with a level of uncertainty in what she is saying.

Theme 4: It's not got a name: Labelling and medicalisation

There are many instances in Sarah's story in which she references her diagnoses and medical experiences she has had. She experiences being labelled as positive and the lack of label for her physical disability seems negative. Below is Sarah's description of her physical disability:

2. Yeah my disability is probably at the mild end so, I was born with my left foot deformed and so that sort of my toes were pointing the wrong way so I had surgery when I was really small and then surgery when I was 14 so I suppose, it's not a named disability but it effects my gait and how I walk and pain etc. and I'm also Dyspraxic so that doesn't help but I think it is my whole left side, to some degree, it's not got a name

She states that it doesn't have a name, and repeats this. This suggested to me that it having a name would hold meaning for Sarah. Not having a named disability seemed linked to its 'mildness', I wondered if she would have added this caveat to its description had it been a named disability?

Reflection 19: Not having a familiarly named disability myself, I felt Sarah's need for this, for the easiness it affords you in interactions with others. the acceptance that it may bring when you can tell people something about you that is familiar to them, and this verbal or non-verbal responses you can receive when you start explaining something that in unknown territory to most. The awkwardness, the apprehension and defensiveness I feel when having to do this was presented to me.

Here we can see that not only was her impairment not named but it was also not termed as a physical disability, this lead to confusion for her.

13. I didn't like it I suppose, well at that time I didn't know I had a PD as such that was what I'd grown up with and no one ever mentioned that that's what it actually IS – I suppose you could see that my foot looked different had scars on it etc. I guess cause I didn't know that that was what it was, it was a little confusing

I felt this meant a lack of acknowledgement for her; there was no narrow label, but no broad one either. What did that mean for her in terms of validating her needs and the pain that she described in the passage above?

That lack of label was perpetuated at many levels and interactions:

15...if you go to the Doctors they like ‘hmmmm’ or google it there’s nothing, so technically I’m an amputee, but that’s only, that’s if I’m being very technical

I found the sentence ‘*technically I am an amputee*’ very interesting; wasn’t she allowed the label of ‘amputee’? Who had decided so? It raised a story related to counting, as we have seen elsewhere in Sarah’s story but also about the importance of language, naming and recognition. Admittedly if Sarah had introduced her disability stating ‘I am an amputee’, this is very clear, very definite. I wondered whether Sarah didn’t feel affiliated with the term or whether she didn’t think she deserved the term – linking back to her feelings of being fraudulent and feeling guilty. I am aware that there are many people in the disability community who are amputees and I wondered whether this was another intersection that Sarah wasn’t allowed to align with.

Next we can hear Sarah’s perspective on being labelled:

29. Erm...well I’ve...well at 19 I was diagnosed with dyspraxia and Autism at 21 so I suppose it has all sort of merged into one, so I now understand a few more things but I think particularly the dyspraxia, the physical stuff, I knew I could never hold a pen and the walking etc. but having that, means that at least I can say to someone ‘Oh I’m dyspraxic’, even if that’s not quite the route cause but it’s something people have heard of and is easier to explain than saying like the ins and outs of how I was born – like cause that’s the only way I can explain it really

Being labelled seems to have been a mainly positive feature in her story, giving her an explanation that is quick and convenient to justify herself and her needs to others. It gave her an understanding of her own adolescent experiences. Having these labels seem to help depersonalised her disability making it easier to share. Can align with a group when she says she is Autistic and/or Dyspraxic.

33. It’s just easier cause people know what that means and they just don’t understand the other stuff, and there are also other people that have dyspraxia like I can’t, like, I have extensively tried to google, but there obviously will be people who have the same birth deformities but I can’t find them...

We can see here how not having a clear label of her impairment seems to prevent Sarah from forming connections with others with a PD. The need to have labels in society has helped but also hindered Sarah in her search for connection.

50. *It was ok, I suppose I had some mental health issues but they weren't really related to this, so err but yeah if I said like my foot hurts that's like the only thing my parents would say right let's stop but if you said something else they'd be like ok you're fine....*

Below, Sarah shares how important gaining a label and gaining confirmation via the PIP process gave new meaning to her disability identity:

60. *I think getting the other diagnosis and applying for PIP has made me view myself differently because I've got quite a high, well highest care and normal mobility I suppose in my head I'm like well if I've got that then there clearly is something that's a bit different even if I sometimes I think of its mild and I dunno if that's cause of other people going oh it's not that bad etc. so I suppose I think that's reframed it in my mind sort of but then a physio said to me the other week, "well you wouldn't could yourself as physically disabled would you?" and I was a bit like, hmmm... so I don't know I think its cause I can hide it quite easily where as if I was a wheelchair user you can't hide it...*

Reflection 20: It was very interesting to me to hear a positive take on being diagnosed and receiving PIP. How it was affirming for her and helped her come closer to her disability identity. I find that, having a rare condition, I do not have the same access to affirming feelings through diagnosis as Sarah does. And very differently perceive the PIP assessment and process as one of the most oppressive, degrading experiences of my adult life. I suppose it highlights the difference in identification when you are diagnosed at birth or later in life.

Furthermore, this made me reflect on my practice as a Trainee EP, in which I generally express that diagnosis is of little importance (when it comes to school support that can be provided) but perhaps more emphasis should be placed on what diagnosis means for the individual and their disability identity formation, in my work.

Further to this, Sarah describes her reaction to gaining diagnoses of Autism and Dyspraxia in university:

75. *When did you receive your other diagnosis?*

76. *19 and 21*

77. *First year of Uni? How was that for you?*

78. I was quite pleased to get the dyspraxia one because I'd always had trouble with writing and PE etc. and it was always put down, to and then I always had difficulty reading something wasn't quite right that couldn't explain and that was quite good as well and like the coordination.... Like I use my left hand to steady myself so even if I'd made the coordination work... I wasn't born that way it reassured me that I had something I could explain

79. How about if you had that diagnosis earlier?

80. I think it would've helped a lot, not just physically like with reading and things but yeah in PE it would've helped a lot for people to know I had a thing – cause people were quite nice to people when they knew they had something, like dyslexic or,... but there was also a culture of oh you're just trying to get an advantage

It is interesting how being labelled has been a positive and negative experience in Sarah's story. It is also interesting that it helps her on an individual level to know and be part of a group but that this is influenced by the responses she has had from others. At school she felt more accepted by having a diagnosis, she feels connected to Autism and is carrying out her research in this area.

Finally, this is the moment Sarah identifies that not being pathologised and connecting has been a positive experience for her:

134. More, I suppose its shared experience so, I'm more used to participating in Autism research where the researcher is not autistic at all, and erm, there are usually several questions that allude to intellectual ability or you can't do X, Y, Z or ask you why, cause they don't have any personal experience at all, it's a bit easier cause you don't have to explain everything from zero.

For me, this highlights the importance of having her voice heard and sharing her experience from a social view of disability. In the Autism research, it sounds as if she was a 'subject' and in this piece

Reflection 21: I was both pleased and relieve that I have been able to create this space for Sarah where she has felt a part of the research rather than a subject to be questioned and assumptions made about her abilities.

Not having to '*explain from zero*' is something that I appreciate when discussing my disability and for such a small point, it holds considerable meaning – it says to me 'my disability matters' 'I have a connection with you' and means that knowing and sharing is important for true understanding.

4.4.3 Characters: Unhelpful helpers

As we can see from the theme '*It's not got a name: Labelling and medicalisation*' medics play a crucial role in Sarah's story. From her mother who was a doctor, to physiotherapists, to medical diagnoses. Her friends play a brief role in her story and provide a positive in her story of adolescence; they provide connection for her through their similarities. Her wider peer group play a negative role in her story, some were bullies and some outside of the school environment made comments which have lasted with Sarah into adulthood.

Teachers play a positive and negative role in her story. The teacher who noticed that she was upset in class seemed key. Showing the importance of such small interactions and acts of empathy, it seemed significant to Sarah, enough to form part of her story. Medics have played a key part in Sarah's story; they have provided her with reassuring diagnoses but also with judgements which have disrupted her view of herself as disabled. The interaction between her Mums also being a medic is interesting, making her a complex character in Sarah's story.

The public have featured more than once as characters in Sarah's story, their judgements and comments alike have impacted her view of herself and her disability. It seems that throughout Sarah is aware of them as an audience as if she has been narrating a live show. They are in sat in waiting like a judgement panel ready to term her too middle class, not disabled enough. Interestingly researchers also feature, she is currently a researcher herself, but having taken part in research she highlights that they are generally able and aiming to discover the difficulties she may have due to her Autism, something she expresses is uncomfortable.

All in all, the characters in Sarah's story who's role it is to help, are (albeit subconsciously) unhelpful in her disability identity narrative. They both affirm her identity and some difficulties

she faced, as with the teacher example above. Her family are supportive, however did not acknowledge her disability as she perhaps wished they had. He had friends in school; however she experienced bullying from her peers.

4.4.4 Emotional hot spots

Sarah's response to the magic wand question, that she would change her parents' perspective on her disability was very emotive for me and seemed so for her. It felt confessional to a degree and must have been quite difficult to share with an unfamiliar person. It was a surprise to me as the researcher but perhaps showed that the shared space we had created was safe and we could broach difficult subjects together.

Further to this was the following passage regarding her parent's views on her impairment:

52. ... they are supportive with it, but I suppose there's nothing they can do, I think that sort of hurts my parents, I think my mum feels blamed because it was a random thing but obviously...

For me acknowledging this fact takes a high level of empathy as it can lead to feelings of guilt for the individual. I can't be clear as to whether this is the case for Sarah, but it certainly was for me. Guilt is referenced elsewhere in Sarah's interview relating to identification.

53. Same here. It's really interesting, the dynamic, I had surgery at 13 so on crutches and in a chair for a while in high school and its funny that you had the similar experience and for me it was a trigger point for me and not being happy with my body

54. I felt that, if I think back, that's the point that Yeah bit of trigger

In describing herself as an adolescent, post-surgery, Sarah shares this emotive piece about her experiences:

7. Very shy, reserved and sort of, very anxious and it almost feels like that was, there's post-surgery depression that you can get I think maybe I got that or something, something just changed

This description was triggering for me particularly as I had a very similar experience as described in the literature review; I was told that depression following surgery was normal,

and it was dismissed. Sarah identifies this as a trigger point and it depicts her making a connection between this experience and the way she feels now. As she said, something changed, but I got the impression from her that this change, her anxiety and depression were over-looked.

4.4.5 Imagery and Metaphors

Very few images and metaphors were used in Sarah's story; she had a pragmatic approach to recounting her experience. However, some reoccurred such as being fraudulent, as in the initial theme. It was a strong choice of work seemingly describing a strong feeling. In my view it is powered by ableism and the impact of abled opinions on what counts and does not count as a disability. This is perpetuated in Sarah's views of herself and that fact that her impairment does not have a name.

Linked to the theme of 'Invisible and visible', Sarah referred to herself as Plane Jane in her adolescence, as not really having a 'strong identity'. I wondered if being a 'plane jane' in her adolescence was a form of 'passing' for able, not only did Sarah not identify with being disabled but didn't identify with any of the fashions or trends at the time. Perhaps so she did not want to be noticed.

4.5 Part 2: Sarah's I Poem

Please see Appendix 8 for the full piece, where the 'I poem' is set into stanzas that were naturally developed through the flow of conversation. The stanzas are in the order in which they appeared in the transcript. Throughout Sarah's 'I poem' there is a tendency to 'suppose' and 'think' that comes through clearly in the full text. This links with the themes I have drawn from her interview in that she is in a place of confusion over her disability identity and where she fits within her social class.

The most powerful stanzas for in terms of responding to the research aims of this study are, Stanza 3:

Grappling with her disability identity:

I didn't know I had a PD

I suppose

I guess I didn't know

I suppose I don't actually have one

I feel a bit fraudulent

I don't know

I can walk basically

I suppose

I'm an amputee

I'm being very technical

Sarah speaks about herself in uncertain terms, it relates to the theme of 'Lost in the intersections'. There are only two lines which are definite, that Sarah can walk and must therefore not be disabled (in line with dominant stereotypes), in her debate with herself regarding definition. And 'I'm an amputee', which was caveated with 'Technically' which gave her story a title. I interpret this as a Sarah speaking in tentative terms with regards to claiming her disability status, as if claiming it would be taboo.

Furthermore, Stanza 21, as follows:

Magic Wand

I think I would have changed my parents view on what I had

I think I'd probably, yeah, if they had told me

I suppose if I had then been comfortable

I think that would've helped

I think school there was no sort of

In this stanza Sarah links being comfortable with having the disability identity shared with her by her parents. She identifies that this could have helped her and this links to the theme of 'It's not got a name: Labelling and medicalisation' and raises an interesting point about the parental role in disability identity.

And finally, Stanza 24, which addresses Sarah's involvement in the research and shared experience with me:

This process

I haven't really had any

I suppose unless you disclose you can't really tell

I suppose its shared experience

I'm more used to Autism research

I don't do research and delete the emails

I didn't, so obviously something clicked

I wanted to talk

This stanza starts with her lack of shared experience and the interview being one of the few instances of this. It leads onto a change in behaviour between the concrete 'I don't do research' and 'I wanted to talk' showing the impact of having the opportunity to engage. For Sarah being invited to complete research with a disabled researcher, gave her the opportunity to have her voice heard, on a level that she changed her actions based on a possible need to express her story.

4.6 Part Three: Sarah's Contrapuntal Voice's

The themes of 'Feeling fraudulent' and 'Invisible and visible' are linked in Sarah's story. In the latter, visible is legitimate. Her disability is legitimised by others; by interactions Sarah has had in the times she has had a visible difference. She was affirmed by that as an adult, she explained that this made her life easier in terms of people's levels of empathy. Conversely, being invisible seems linked with being fraudulent. Because her physical impairment can easily be missed by others, Sarah seems to wonder if it counts at all. Sarah highlights the discrimination within discrimination that her other disabilities count as invisible and they are legitimate but her physical disability '*isn't a thing that exists in the world*'. In some ways the characters in Sarah's story have facilitated her narrative of invisible and visible, particular the comment from the Physiotherapist that she surely '*wouldn't consider herself physically disabled*'. Sarah seems to gain reassurance of her disability status in facts and processes, such as the disability benefits (PIP) being given and her diagnoses in early adulthood. Interactions such as the one with the Physiotherapist must create confusion for her as a result. She seems to prefer to have concrete evidence that she 'counts', that she is disabled and that that is confirmed. It makes sense that Sarah feels this way when societal, familial and medical influences upon her have caused such contradiction. I got the impression from Sarah that mostly, the conversations she had had about her disabilities and impairment were conducted from a medical model perspective:

131. *Final question, how have you found this process? Shared experience?*

132. Quite good

133. *Sorry you are on the spot, that question came from the fact that I have not had much contact with other disabled people*

134. I haven't really had any conversations with anyone else, cause its invisible and I suppose unless you disclose you can't really tell

135. *That's true, that's good, yeah has it been more or less comfortable with me being disabled?*

136. More, I suppose its shared experience so, I'm more used to participating in Autism research where the researcher is not autistic at all, and erm, there are usually several questions that allude to intellectual ability or you can't do X, Y, Z or ask you why, cause they don't have any personal experience at all, it's a bit easier cause you don't have to explain everything from zero.

Despite this Sarah remains unclear about her status but interestingly in coming forward to take part in the study this may have been an opportunity to 'count' through a decision made by herself rather than through other's interactions. She acknowledged this here:

141. Ha-ha yes that says something, well usually I don't do research, and delete the emails but I didn't so obviously something clicked and it was something I wanted to talk about so that's interesting.

I wondered whether, because this study gave Sarah an opportunity to identify herself autonomously, it gave her the choice of being visible on her own terms. This perhaps gave her the legitimacy to get in contact with myself and to very much be counted as a women with a physical disability.

4.7 Summary and findings across both stories

Although it was not my intention to create a homogenous group, for the reasons I provide in Chapter 2, several similarities can be seen in the stories which I felt needed to be addressed to retain authenticity. I will refer to them here in terms of theories which may help explain the participants' experiences.

A sense of belonging is missing from both stories, for Alex, she struggled to belong at school and within her culture. For Sarah she struggles to belong to her many intersections, of class, gender and disability. Belonging is something that features in social theory; Maslow's

Hierarchy of needs (Maslow, 1954) identified belonging as a basic human need, ranking it third in his hierarchy. In his model, it is an essential step to having self-esteem, respect and ultimately self-actualising (being the best version of you that is possible). Anant (1966) suggested that belonging is '*the missing conceptual link in understanding mental health and mental illness*' from a relationship/interactional perspective. Belongingness was defined by Anant (1966, p. 21) as a:

"Sense of personal involvement in a social system so that persons feel themselves to be an indispensable and integral part of the system".

Based on my interpretations of their stories, each of my participants have been excluded in some way from their 'social system' and have not, until adulthood been treated as '*integral and indispensable*'. When they have experienced this, they have largely done so through their own efforts, such as their career choices. This was driven by a need to process their own past experiences, as in Alex's case, and to further understand their disabilities. Furthermore, Mahar, Cobingo and Stuart (2012) define belonging as '*a subjective feeling of value and respect derived from a reciprocal relationship to an external referent that is built on a foundation of shared experiences, beliefs or personal characteristics*'. A sense of being valued and respected during their adolescence and at times now, was not a theme in either story. There were no shared experiences, beliefs or personal characteristics available to them meaning that the '*foundation*' of their belongingness, wasn't there to build upon.

On an individual level, experiencing exclusion through systems, peers and class or culture may have impacted on their sense of belonging, but these factors also seemed to impact their view of themselves. Alex clearly described internalising the negative comments made by her peers and internalising her self-deprecating comments. The impact of this could be viewed using attachment theory, a term developed by John Bowlby from the 1950s onwards. The way we connect with others and the relationships that we make, alongside trauma and loss, can impact the way think of ourselves; Bowlby termed this our '*internal working model*'. Originally, this model has been used to describe the relationship between children and their parents. However, teachers, peers and other professionals have very close relationships with young people during their adolescence (Bretherton and Munholland, 1999).

It is my view that the lack of acceptance which the participants experienced in my research, from these characters, could have impacted their internal working model on an individual level. The impact of Alex's mistreatment (bullying, being hidden) may have impacted her internal working model and lead to her believing negative thoughts about herself. Sarah also experienced bullying in school, though she did not describe this as internalisation, she

reflects on her adolescence with anxiety. According to Murray and Pianta (2007) *'school-based programs designed to promote positive relationships between teachers and students with disabilities, may have the potential to provide these students with much needed support'* within the contexts of education.

Unfortunately, both participants expressed that they did not have such teaching during their time in school. Therefore, the learning that has taken place through their interactions and through wider societal influences may have been internalised. This can be seen in Alex's theme of 'Hiding' and Sarah's theme of 'Visible and invisible'. Both participants were given the impression that it is fundamentally not acceptable to be disabled during their teenage years. The 'teaching' they received centred on the able bodied ideal, as were their friendships, and to some degree the medical professionals involved in their lives. Alex makes a clear reference to internalising the comments made by her peers and herself and the negative impact this had on, what could be termed, her internal working model. What this suggests in terms of each of their stories is that characters play a crucial role. The immediate relationships they had in their teens seemed highly important to the way they saw themselves as disabled women. The effects of interactions they had both positive and negative, were long lasting. Each has found ways to connect with other disabled people to develop relationships with those whom can relate, empathise and are open to learn about the disabled experience. However there is no reason, practical or intellectual, for this experience to be missing from their stories. I believe that in framing this from the position of teaching and attachment, which is commonplace in many schools, could make disability studies connect with education in a way that it currently does not seem to.

At the time of adolescence, it may have supported my participants to have intervention to support their disability identity development. Like all children during development, scaffolding their learning is beneficial (Maybin, Mercer & Stierer, 1992; Gibbons, 2002). Providing learning about disability and what that meant for them may not have been any different to other learning experiences in my view. This teaching may have been worked into their narrative of what it means to be disabled and female. As with all other aspects of learning, this can be thought about using the Zone of Proximal Development (ZPD) which has been defined as:

"the distance between the actual developmental level as determined by independent problem solving and the level of potential development as determined through problem-solving under adult guidance, or in collaboration with more capable peers"
(Vygotsky, 1978, p. 86).

The support of adults in each participant's life could have facilitated them to learn about themselves, their disabilities, others and the wider disability culture. Attempting to learn and problem solve alone seems to have lengthened their process of disability identity development and although both participants are successful and frankly impressive young women, their route to being so could have been a smother one. This aligns with Scofield, et al. (1980) approach to adjustment to disability; the idea that a person's adjustment process is influenced by the environmental events and components that surround a person. People, agencies, and other external forces (such as policies, legislation), have a role in placing expectations on disabled people regarding how they are to meet societal standards. Scofield et al (1980) claimed that persons with disabilities often absorb these messages which then influence how they adjust to their disability and set of circumstances.

On reflection, my initial personal reflection that ideas of disability as a culture and a community seem to be more prevalent in research and academic literature than anywhere else seemed to be the case for both Sarah and Alex, and indeed in my own story. Both participants highlighted a lack of information about disability being shared at school and elsewhere in their adolescent development; both Sarah and Alex acknowledged that they would likely have found this helpful. This connects with Trieschmann's (1980, 1988) findings that education about disability could help disabled people improve their coping process. The stories shows that the participants were and are, dually navigating both the internalised understanding of their impairment, in addition to society's broader meaning making around their disability as suggested by Forber-Pratt et al. (2017) and that this did in fact impact their identity development.

Chapter 5: Discussion

5.1 Introduction

In this chapter, I will address the overall findings of the data analysis in reference to the literature review, my aims and research questions, reflections on the quality of the research (in relation to the criteria outlined in Chapter 2: Methodology) and finally, the implications for further research and Educational Psychology practice. To recap, here are the research questions I aimed to answer through the data analysis:

1. What stories do two post-graduate women who identify as physically disabled tell about their experience of adolescence?

2. How do they reflect on these stories in terms of their identity development during adolescence and into adulthood?
3. How are both the researcher and participants affected by engaging in narrative interactional interviews?

5.2 Disability identity

We can see that the stories told by the participants are ones of great depth and some challenge, and that they are both ripe with overtones of ableism from various characters and structures involved in the narrative. For Alex she reflects on her adolescent pragmatically and with a dark humour. For Sarah she reflects thoughtfully on the various identities she could align with. Over all, the reflections of the participants' past experiences with their current sense of 'self' connected their past and present (Bluck and Levine, 1998). What Linde (1993) termed '*autobiographical reasoning*' can be seen to be taking place in each analysis as they tell their stories biographically, revealing a developmental history from adolescence to the present. Though they are two different stories, we can see similarities in the themes of 'Hiding' and 'Visible and invisible' and certainly in the development of each story into one of affirmation and a move towards a stronger disability identity.

Sarah and Alex referenced the intersectionality of being female and disabled in their stories, as a negative aspect of the disability identity development. Alex referred to peer pressure and the expectations for women in terms of body image and how they are viewed by men. Sarah, in particular suggested she found being a disabled woman difficult as part of a combination of other intersections she experiences such as class. This links with Rousso's work around the 'double disadvantage', referred to in the literature review.

Both participants referred to the expectations set out for them by their culture, which are based within the dominant societal influences in which they grew up. For Sarah, the medical model was pervasive, from her parent's views, to her involvement in studies as a PhD student. For Alex, the dominant narrative of her home country impacted on her access to identification with the label of disabled. As in Goodley et al.'s (2017) work, both participants have experienced de-humanisation, including in school; most poignantly in Alex's story regarding segregation from her peers. To recap, Campbell (2009) and Banks (2015) define ableism as '*attitudes and barriers contributing to the subordination of people with disabilities in liberal society*' it seems that both Sarah and Alex experienced this as in their adolescence through their separation from their peers and lack of consideration of their needs.

For Sarah, overt stereotypes of disabled people as discussed in the literature review such as the rhetoric around fraudulent disability benefit claims (Zhang and Haller (2013); McEnhill and Byrne, 2014) is something that has impacted her disability identity. Hughes (2015) idea of the 'counterfeit citizen' seems to align with the theme of 'Feeling Fraudulent' in Sarah's story. Conversely, Sarah's conflicting class and disability experiences, resonate with the findings of Campbell (2009) who suggested that white women are at risk for '*internalized disableism*', due to the associated loss of white privilege. In terms of the definition of disability from a social constructionist perspective, Anastasiou and Kauffman (2013) purported that, despite the fact that disability is part of human diversity; '*it is not simply another difference and cannot be synonymous with social disadvantage*'. It seems that this point of view, challenges the relevance of the purely social model in explaining Sarah's experience. Her perceived social class, and disability, clash with one and other, challenging the stereotype of disabled people being 'without'.

An interesting finding in Sarah's story was her positive description of receiving diagnoses; this is somewhat contradictory to Connor et al's (2008, p445) view that there is a '*use of damaging labels and deficit-driven medicalized conceptions of disability*' in education. Sarah's diagnosis seemed to affirm and strengthen her identity as she appreciated there being an explanation for her dyspraxia, for example. This perhaps highlights the importance of individualised accounts of being disabled and identification.

5.3 Identity and self esteem

Both participants refer to negative feelings towards themselves and their bodies in their stories. Through the interviews and analysis we (the participants and I) linked this to external societal pressures linked to ableism. Erikson claimed that in adolescence, pressuring someone into an identity (in their case it was being pressured into being 'able') can result in rebellion in the form of establishing a negative identity, and in addition to this feeling of unhappiness. This could explain the challenges they faced with identification, hiding and invisibility in their development.

Both participants' narratives are relatable to Erikson's idea of 'role confusion' which could occur in any able adolescent, and involves the individual not being sure about themselves or their place in society. For Sarah, her 'role confusion' is clear in her narrative; particularly notable in the theme of 'Lost in the intersections'. According to Erikson, in role confusion, an adolescent may begin to experiment with different lifestyle (e.g., work, education or political

activities). This can be seen in Alex's story, in the theme 'Hiding', in the way she describes interacting with boys, her dress and for both women their choice or profession seems in some way semi-political act and life style choice that was linked to their disability identities. In each individual story, there is a sense of having to untangle their identities. As Erikson's theory suggests, adolescence is a time of figuring out and learning through experience that I accept. However, my participants both told stories which were missing characters who they could relate to and who could support them in their development. Meaning that, they were, and in some ways still are untangling the confusing landscape that is developing an identity as a disabled woman. For me, this isn't a situation that needs to be quite so lonely and difficult if only it was facilitated and the right support was delivered.

5.4 Shared experiences and Belonging

By engaging in the shared experience with me, both Sarah and Alex claimed that this was a positive experience. This relates to Putman's (2005) suggestion that there disabled people feel an affinity with others who are disabled. We can see this at the end of Sarah's story as she describes her decision to carry out my research, when usually she would choose not to engage. As Putman claimed that Disability identity is an important '*adaptive psychosocial construct in the lives of many people with disabilities*', we can see that both Alex and Sarah have used their disability identity as a tool to enter careers in special education and Autism research, respectively.

As in Hanková, and Vávrová's (2016) study in which graduates experienced considerable distrust of their classmates and a reluctance of the teachers to accept their specific needs. Both Sarah and Alex highlighted the lack of interpersonal communication and cooperation and the lack of shared experiences in the school environment in their stories. This relates to Doubt and McColl's (2003), idea that disabled participants' '*sense of integration through peer and staff support, negative reactions and inaccessible activities*'. Inherent factors that the researchers highlighted, such as '*strategies of self-exclusion, masking their disability, finding a niche and making fun of the disability*' each play a part in my participants' narratives. Particularly for Alex when she describes her self-deprecating approach with her peers, who bullied her, in the theme 'hiding'.

As explained at the end of the previous chapter, both Sarah and Alex's stories have subliminal themes of being excluded and not belonging. Themes of belonging and identity, particularly group identity are congruent within the literature. In basic terms, if you don't feel that you belong, your identity is unclear to you. Maher, Cobigo and Stuart (2012) explained that '*external connectedness is grounded in the context or group to which one chooses, wants and feels permission to belong*' for Sarah and Alex, permission to belong to their

school, or peer group or indeed to the disability community wasn't given, their wants and choices weren't adequately heard. However, by engaging in the interview and their careers, external connectedness and permission was provided to them.

5.5 Developing a positive disability identity

In the context of developing a positive disability identity, Dunn and Burcaw (2013) factors affirmation of disability, communal attachment and personal meaning; feature in each story through the shared experience and seem to be connected with a positive identity development. Furthermore, Darling's (2004) idea of 'crusadership' can be seen in their career choices and choice to engage in the research.

Towards the end of both stories, both Sarah and Alex explained how they have resolved (or at least in part) the challenges they faced in adolescence through their actions, predominantly their career choices and engaging in this research process. This is in line with Campbell's (2009) suggestion that in order to 'survive and thrive' in a society heavily influenced by ableism, women with disabilities must develop healthy disability identities. Relatedly, their stories and my own, align with Enns' (2010) writings which suggest that identity development is a transition from '*accepted internalised oppression to flexibility*' which leads to positive attitudes toward disability.

5.6 Coming out and Passing

In terms of the parallels that can be drawn between other communities, such as the LGBTQ+ experience, for Sarah she is not secure in this identity in her own mind but also shows the great impact of external societal influences can have on someone's identification. This adds complexity to 'owning' the disability label when compared to claiming other labels, using LGBTQ+ for example, you are not assessed, you are not commented on by professionals when identifying in this way. For this reason and based on the narratives provided, 'coming out' as disabled is a very different process. This relates to Swain and Cameron's (1999) claims that adopting of a medical model of disability and being categorised by others as disabled does not count as coming out as disabled. This can be seen in both narratives, both participants were identified by medical professionals and their parents however these were not acts of 'coming out' and seem to have been oppressive.

This also aligns with Samuels' (2003) idea that the 'coming out' analogy limits the idea of coming out itself which can entail a variety of meanings, acts, and commitments. Samuels suggested that the narratives of people with 'hidden impairments' like those of people with other nonvisible social identities, are inundated with themes of coming out, passing, and the imperatives of identity. This is certainly something that both participants, and myself, have

expressed: passing in adolescence and at times now, and 'coming out' by taking part in the study and engaging in careers linked to our own disabilities.

However, in terms of understanding the participants experience some terms from Queer theory were helpful for description such as Garber's (2012) idea of category crisis which people with nonvisible disabilities (and those members of the LGBTQ+ community who are not 'visible' e.g. those termed in the LGBTQ+ community as 'femme lesbians') provides an ideal analogy to explain Sarah's experiences in particular. Samuels (2013) suggests that societal discourses about appearance have led to in a typically exclusive emphasis on '*visibility*' when it comes to each community and to enacting social change.

Over all, I feel the narrative data I have developed is in line with Dunn and Burcaw's (2013) view that such narratives can give people with disabilities and others in their lives, a source for learning from the psycho-social experience of disability and understanding their stories. Sarah and Alex's stories, along with my own reflections, have provided first-person accounts which reveal and endorse '*appreciation for the common and unique factors that shape the experience of disability*', (Dunn and Burcaw, 2013) in this case, being disabled women.

5.7 Reflections on the quality of research

In terms of the quality in the data of this research I have expressed that the participant's narratives are their 'subjective truth' as is typical in narrative research (Bakhtins, 1986; Moen, 2006). The different perspectives of the participants have been represented, the LG methodology has given space for their subjective positions from which they experience and interpret their worlds (Peshkin, 1988, 1991). I have, in line with Denzin's (1989) explanation of narrative, provided truths that are constructed between the researcher and the researched. Therefore the 'facts' which are referred to by myself and the participants, refer to events that are believed to have happened, and the analysis describes '*how those facts were lived and experienced by the interacting individuals*' (Denzin, 1989), this is in line with Denzin's writings that means that 'true stories, are those that are believed'.

5.7.1 Dependability

Through the use of the Listening Guide, I have held the research in line with the interpretivist stance described in Chapter 2. I analysed the data from an emic/etic stance and as a result of this, interpretation is embedded within the context the stories were told. This therefore affects the replicability of the study. Because the data was co-constructed with individuals, change did occur as their stories developed (Merten, 2015). The data has displayed the

stories of subjective experience available at that place, at that specific time (Goodley, 2011). My data collection methods and recording of the research process promotes dependability rather than reliability and I have ensured that my decisions and outcomes have enough detail for others to follow the procedures. I have also provided a possible extension of the Listening Guide when used in emic/etic research with the 'You Poem' provided. I have made the procedural information available to the reader and through my reflection boxes I have shown an example of reflexivity in my analysis. The procedure and analysis is accessible with clear procedures, transcripts and analysis to support its dependability (Polkinghorne, 1988).

5.7.2 Validity

With Lincoln & Guba's (1985) notion that validity is a redundant measure for qualitative research, my research instead can be assumed to be 'well-grounded and supportable' (Polkinghorne, 1988: p.175). I have done so with the use of verbatim quotes and engaging the participants with the data collection process meaning there is trustworthiness and credibility rather than validity. The narratives provided are accurate and authentic and I have approach the research with integrity. The research does provide what I consider to be a procedure that is replicable for use with any research wishing to hear stories of the marginalised group of which they identify with. Trustworthiness has also been promoted by my engagement and interaction with the participants, providing faithfulness to their experience through reoccurring involvement, reflective and reflexive practice. Through the use of auto-ethnographic and narrative approaches I have provided a comprehensive analysis (Lincoln & Guba, 1985; Carr, 2013).

5.7.3 Generalisability and reliability

In line with the narrative approaches, my research relies upon a small participant sample and has a richness of data over broad generalizable data; it is case centred (Riessman, 2008). The analysis gives voice to women with disabilities, as was its aim. I have rejected the notion of generalisability as part of the rationale of my research. I have achieved a data set that ensures that I deviated from assumptions that disabled people can be considered as a homogenised group. In doing do, I do not feel I have contributed to a medical model view which approves generalised assumptions and, even if unintentional, prejudices. Instead the research purposely has challenged the dominant disability discourse described in Chapter 1: Literature review.

5.7.4 Transferability

I recognise that there may be some transferable elements in the data analysis, but it is not my intention to force shared experiences of my participants on the disabled female population. In line with Moen (2006) I have provided a rich data set that draws on the individual, their social context and actively listens to the multiple voices in their accounts through the use of the LG. I have therefore provided narratives that ensure readers can transfer the information to further settings. Readers of this research can therefore determine whether the findings can be transferred based on any shared characteristics in their demographic (Creswell, 1998). In terms of the data analysis, it is important to recognise that some researchers (Barone and Eisner (1997); Piirto (2002) claim that using techniques such as the LG can mean a risk of *'interrogating dominant narratives'*. They claim that it is unfamiliar, and it pushes the boundaries of traditional research. Though I accept this critique of such a method, I would argue from a feminist stand point that it is essential to interrogate dominant narratives when such narratives might cause psychosocial harm to those oppressed by them.

5.8 Reflections on the interview process

As an emic/etic researcher, I feel that I was successful in forming a coproduced piece of narrative research and succeeded in providing a non-judgemental and 'safe' space for myself and the participants to share stories. However at times I found it difficult to retain the researcher position when carrying out the narrative interview. This means, as is clear from the transcriptions, I entered into a more conversational style at times. On reflection, I neglected to apply narrative techniques meaning that I missed opportunities to gain a richer understanding of the participant's comments. It also meant potential missed opportunities to explore certain areas of their stories or to thicken the meaning they were expressing. Therein lays an area of development for both myself as a researcher and the research in terms of validity.

However, the conversational style I adopted for the interview was very positive for rapport building and for putting participants at ease. This can be seen from interactions in the utterances included in the analysis. Unlike a one way interview, it gave me the opportunity for sharing findings from the literature review, areas which I thought may be of interest to the participants and this helped guide the narrative so that the participants could extend their points in context. This also gave me an opportunity to share what I considered to be their information as disabled women. Interestingly, this sharing of information was not a one way

process, during the interview with Alex she raised the idea of female representation that we had witnessed in the media during our adolescence and connected this how we view our bodies as disabled women. In Sarah's story, she raised the factor of class and related cultural expectations. Both of these points were new considerations for me and it became a learning process for myself as a researcher. This is a positive justification of reciprocity in narratives interviews and an example of the value of coproduction. The narrative and interactional methodology also gave my flexibility to deliver each interview differently, with Alex she was very expressive whereas Sarah needed more guidance (likely due to being unfamiliar to me).

However, according to Scotland (2012) in interpretivist research participants' autonomy and privacy can be compromised as the methods of interpretive research are more intimate and open-ended than scientific research. Being intimate in this way, may facilitate the unintended discovery of secrets, lies and oppressive relationships (Howe and Moses, 1999, p. 40). Scotland suggests that participants in such studies have limited control and are vulnerable to researchers imposing their own subjective interpretations upon them. I made the utmost attempt to control for this by providing fully informed consent, with information detailing the study's aims. I also returned to each participant to 'check back' on what they had shared with me. Regardless of these measures, the analysis did feel very intimate and I have felt a discomfort with analysing such personal accounts, particularly when it came to commenting on familial influences on their identity development.

The time given to complete the research was limited; this meant that it was not possible to have several meetings with the participants to thicken their narratives, which could have given a richer data set. If I was to repeat the research, I would request a follow up interview and perhaps encourage the use of photographs, diaries etc. as prompts for the participants. This could have enhanced their ability to narrate their adolescence. I may have encouraged them to write a reflective account of their adolescence to analyse alongside the audio interview data.

Furthermore, for the Sarah who was unfamiliar to me (unlike Alex); it may have been more inclusive to have offered alternative methods of gathering data from her, as at times, she appeared to find the more personal and probing questions difficult to address. Perhaps more time to develop a rapport with her may also have been helpful, regardless of any diagnoses, face to face interviews can be an intense experience. Other than this, I felt that the study gave consideration to disability access for both of the participants.

In terms of the method of sampling, using the university based group email system to gain participants did mean I would likely receive responses from a certain socio-economic

demographic and those of a certain level of education. Although intersectionality of disability and class is referred to in Sarah's story, as the researcher, I feel I perhaps could not give space for participants with different socio-economic backgrounds, and therefore different life experiences. Should the study have been carried out over a longer period of time, I would have extended the search for participants to the wider community to ensure a wider range of participants from the disabled community.

As Wheaton and Crimmins (2016) noted, education helped explain sex differences in their study regarding outcomes for women with disabilities. In other words, where women with disabilities were better educated their needs were less impactful on their activities of daily living. Both the participants and I are educated, and our outcomes appear positive, despite shortcomings in the way we have been taught about disability and our identities. I feel it is important to recognise that this is not necessarily the case for all, and that the study has centred on those privileged enough to engage in post-graduate study, meaning that their access to education could have impacted on their disability identities.

Furthermore, by the chance circumstances made by random sampling, both participants in the study had what could be described as an invisible disability. As the literature suggests, this can be a very different social experience to that of those with an 'obvious' physical disability, this is indeed referred to by Sarah in her story. Perhaps if I had targeted the sampling to disability groups, within a university or elsewhere, I could have involved other disabled people with a variety of experiences. The sampling was deliberate however, and my intention was to enable only people who identified themselves as disabled to volunteer as a participant, as discussed in the Chapter 2. However, I wonder if I had approach disability group/communities, I could have recruited participants, assuming identity by the virtue of assigning to such a group? This therefore leaves room for extension of this study with a larger cohort.

5.9 Implications for further research

Though the research findings cannot be extrapolated and applied to the general population of women with PDs, what it does do is give reasoning for the use of collaborative approaches in further research in disability. It also provides justification for the use of an emic/etic position in disability/feminist research and of disabled people being involved in research about themselves and their impairments.

Perhaps the research could be expanded by including a greater number of participants in a focus group to develop a richer understanding of the disabled/female experiencer. This

would amplify the shared experience for the participants and encourage the 'community and culture' aspect of positive disability identity.

Furthermore, my research provides evidence for the conversational, interactional interview and the richness this can bring to narrative data. Providing access to my own experiences and aspects of the literature seemed to bring an authenticity and honesty to the research that created a safe space for unfamiliar peers to share personal stories.

The research also showed that for both participants, this was the first interaction they had had within another disabled women, and how this had impacted them positively. This means there would likely be justification of a study which explores the therapeutic potential of narratives and sharing experience for women and girls with physical disabilities.

5.10 Implications for Educational Psychology practice

On reflection of the research process I feel there are several factors which Educational Psychologists can embed into their practice on an individual, group and systemic level we, as Educational Psychologists are in a position of relative power, and in a position to challenge practice. We therefore have an opportunity and some would argue an ethical duty, to weave disability identity into the narrative. Particularly when we are aware that this may be linked with the well-being of our clients add value to their lives. The ways in which I believe our practice can be influenced are as follows:

Having the conversation, asking the questions.

For me it is as simple as this subtitle suggests, that is, in our consultations begin to use language that denotes identification, ask the question – do you identify as disabled (or autistic, or with the deaf community)? Ask, do you have any peers with the same needs? I am describing acknowledgement and facilitating young people with the option of exploring this as an idea; weaving disability identity, into the narrative of our clients. Simply by asking the question, young people can be given the option to think about the idea of connecting with others who share their experience. They can think about their disability identity. The same could be said for families. Simply having the conversation in schools with teachers and other educators could also bring these ideas forward. After all, these are the people that will then need to practically facilitate the young people in finding connections or exploring disability through intervention. We need to give young people the option to identify as disabled and indeed to not identify. We do however; need to provide them with an informed choice.

On a formal level, providing and encouraging training around Disability identity, belonging and whole school approaches, could be a beneficial way of transferring the outcome of this research into practice. At a Local Authority level, I believe the research could influence the mind set around other minority groups, such as those who face temporary or permanent exclusion from school, particularly by highlighting the importance of belonging for pupils' wellbeing. Swinton (2012) made the suggestion that we *'need to shift out thinking from inclusion to belonging in order to reframe practices and policies'* this is something that I whole-heartedly agree with. The term inclusion its self alludes to certain groups of children being marginalised in the first instance. Perhaps reframing inclusion as belonging, in out consultations and interactions with settings could make the message that all children belong in mainstream schools and mainstream society, clearer and more connected to the mainstream.

Encouraging inclusion not normalisation: in writing and consultation

A key point in terms of educational psychology practice and other services that support children and young people generally is the point from Campbell, in relation to therapeutic intervention, she stated:

"The pathologisation of disability has meant that therapy predominantly concentrates on normalization and is not necessarily directed to attending to the harms of ableism ([that is] living with prejudice)"

Though therapy is a different field, normalising narratives are something that I have observed in frequently within schools and EP services, and regretfully in my own practice. Under the assumption that we are helping children to 'fit' in through educational inclusion, we may be reinforcing the ableist norms Campbell refers to. When we consider this in the context of disability, perhaps normalisation should not necessarily be considered inclusion.

The data provided within this study from my participants, in addition to the literature reviewed, leads me to question some of the recommendations I have made within my reports as a trainee and question those I have seen in others. On reflection, some recommendations I have made and read suggest ways in which the child or young person can be more 'able' – whether that is socially, cognitive or in self-esteem and confidence. Although I acknowledge that this should take place in some circumstances, I wonder whether recommendations are less inclusive than we might intend them to be at times.

Recently in my practice I have begun to ask young people if they want to change, of they want to be better at socialising for example. I am trying to give them agency so that I can target my reports on their wishes and not impress on them the general idea perpetuated by

ableism in society; that to be successful they need to work on being normal. However, because the ableist influence is so strong it is important to realise that even if we ask if they want to change, their choices may not be their own. That is where targeting teaching and intervention and raising awareness come into the picture.

I wonder if it would also be beneficial and powerful to explore sense of belonging more with children with PD and other SEND in our work. And whether this could be reflected in our consultations and reports, perpetuating the idea that children's presentation may be due to their feelings of exclusion and lack of belonging and how this could be mediated by those around them.

I believe being critical and reflexive on this matter in our writing and consultations is crucial in aiming to help children and young people belong. Reflecting on reports with questions such as: *why do they need to change their behaviour? Is that a target for them or is that a target for the staff on their behalf? Are my recommendations leading ultimately to them hiding, masking or passing? Is this helpful?* For me, these are questions that we can also ask in consultations of other staff involved in a child's education.

Bringing disability identity into the 'mainstream'

Educational psychologists are in an opportune space between practice and research; they can and do base their practice in an evidence base. I feel that this means that we have the ability to share the research findings with disabled young women and with their educators. To share the stats, the information on the possible negative impact of hiding and passing; in turn to share the positive benefits of connecting with the disabled community, which I feel has been expressed by my participants and myself in this study.

A common critique of much of the literature is that it has been carried out by predominantly white middle class researchers (Devlieger and Albrecht, 2000). It is ironically inaccessible to most disabled young women, especially children. As Educational Psychologists, we have the ability to bring this information into the mainstream, to make it accessible, by training and raising awareness within schools. This way we can facilitate educators and all students to learn more about the disability community and their rights. As I have explored throughout, there is a link between doing so and self-esteem and efficacy. As mental health difficulties in young people are on the rise and there is an increased focus on mental health in this profession, those with some 'double disadvantages' should be prioritised.

I feel that as a profession, if we make these changes we will align with the social/affirmative model of disability as best possible. What is crucial for me to acknowledge, is that we are an

integral part of the support system in place for many young women with PDs and other disabilities and special educational needs. We therefore have the ability, by making the changes above, to take some of the emotional weight of finding disability identity, which for my participants and me has had to be carried alone.

Overall, I feel that the research could be a driver to effect change in the way we practice but also in the way disabilities and additional needs of any kind are discussed and met within the systems around them. This can be framed similarly to Bronfenbrenner's Ecological Systems Theory (1994), in that the research is influential through the various layers within the system; from the point of interacting with the child/person, including their family in the process, sharing our expertise in this area with them, influencing teacher practice and training staff, and being critical towards the systems within Local Authorities that may be enabling exclusion and ableism. Above this level, of course is the social policy and legislation that surrounds us. Though this level of the system is difficult to influence, I hope my research can provide a tool for reflection to colleagues around the procedures we consider to be the norm. For example, the SEND Code of Practice which actively requires Local Authorities to ask schools whether they can meet need, and ask for permission to place pupils who have as much right to attend their local school as their able peers, without the barrier of this process (consultation process). Only when you combine the stories of the individuals with disabilities, belongingness and its influence on wellbeing and the importance of identity, does the blatant discrimination within this consultation process come to light. In my view, this shows how essential hearing the voices of disabled people is if we are to effect systemic change.

5.11. A personal reflection of the research process

Completing this research has meant becoming vulnerable through virtue of sharing personal information, through reading material that made me emotional and caused me to reflect, sometimes unwillingly, on discrimination I have faced. I have had to reflect on previous views, assumptions and emotions I once held as being 'truth'. This was a 'sacrifice' worth making as, not only have the participants fed back positively about their involvement but also the research process, has drawn me closer to what I deem my community and encouraged me to develop my own disability identity. It has been somewhat cathartic and near to therapeutic for me as a researcher. It has been an empowering experience both personally and professionally.

Naturally there were challenges for me throughout the process. The first was sampling participants; I had initially planned to have a sample of adolescent girls. On reflection, at this age I would have been extremely resistant to this as I did not identify as disabled. This was an important realisation for me to recognise that despite my disability status I still remained in a position of power and was not 'green lit' to approach others in this way through virtue of being disabled. It was important to remain balanced and ensure no arrogance was included in my 'understanding' of disability.

After amending the study and sending out a search to all students; for students with physical disabilities to respond to, I was hit with a sudden discomfort around the extent of their physical impairment. That is, I was concerned about my own status, as my disability is largely invisible, and what their response to me may be. This certainly caused me to reflect on my own view of myself and concerns I have always carried about 'counting' and not being 'disabled enough'. On reflection I believe this was a concern that was twofold, I was worried about judgement but I was also worried about how the participant would feel about me identifying myself as disabled if they had a more significant impairment. Though I worked through this over time, when Alex and Sarah arrived for the interviews there was a sense of reprieve that I wouldn't have to face that particular tension. This identified to me that at the time that my own disability identity was rather fragile and I still clung onto early affirmations, and broad societal ideas of what it was to be disabled.

Throughout the process, by influence of the reading I carried out but also through meeting with the participants I have connected more with the disability community. As with many current acts of identity politics and representation, this has occurred predominantly online. For me a step towards being represented is being seen at all. It is only through this process that I have begun to follow disability activists on social media platforms, post pictures which include my hands or scars, that reveal parts of my body that I have habitually hidden from view. I have begun to follow and acknowledge accounts which promote political, educational and general societal inclusion.

During the early stages of this process I was asked by my university to present a lecture on physical disability on my course. This acknowledgement of my disability and ownership of it was very significant for me and was certainly a positive step in strengthening my disability identity. I have become more vocal regarding my status in the university and in my placement. I have recently requested to attend the Disabled Workers Conference on behalf of my union. This occurred towards the end of the research process and it is interesting that I did not hold the previous concern of having an invisible disability at this time.

During the latter stages of this process I was interviewed for a full time position at my placement. My disability status featured heavily in the interview and was fed into each of my responses. I presented a case of including disabled people in the process of developing an inclusion charter mark within our service. I was successful in the interview and have since begun developing training for the Local Authority on the connection of successful inclusion of children with SEND and well-being.

It was towards the end of the study and through making links with attachment theory and teaching figures in the discussion, that I had the realisation that I have held on to some negative feelings towards the pupil teacher dynamic. I recognised that I held assumptions about those in “teaching” roles such as my research supervisor, that they are disinterested in me and my work. I must make it clear that my supervision has been excellent and much appreciated in actuality; it is my responses to sharing my ideas and my work that evoke feelings of shame, vulnerability and overall discomfort for me. I tend to be avoidant when seeking help and sharing with them when I am struggling mentally or physically. This is something I have been working through throughout the research process and that I attribute to my school experiences being dismissed and ignored.

As you can see from this chronology, the research process has been far reaching for me. Due to this I feel in a better position to challenge, support others and empathise in my role of Trainee EP. I am more empowered in my work and my personal life. It has been in some ways a developmental ‘coming out’ process, one that is perhaps long overdue. It has been an immersive process aligned with a research process and the two became inextricably linked. Though societal barriers remain for me, as do physical challenges, and I continue to grapple with not epitomising the disabled stereotype, the process has been enlightening and affirming. As a result of carrying out this research I would, with absolute contentment, describe myself as the most disabled I have ever been.

5.11.1 The ‘you’ poem

As part of the data analysis I created a ‘You Poem’ in reverence to the LG’s ‘I Poem’. This aims to capture both participants’ actual voices and their themes, and their contrapuntal voices alongside my own contributions to the interviews. I hope it reflects the outcome of our shared experience. Initially I began writing this poem as a ‘we’ poem, with its aim to connect our three stories and express our shared experience. However, I stopped midway, reflecting that the onus and responsibility for aligning with our identities and culture was yet again placed upon us. This was in fact against what the literature and the affirmation model represents, besides the narratives of my participants. They both expressed a want for others to change in their narratives. By changing this to a ‘you’ poem I hope to corroborate the

participants' feelings and responses to their adolescent experience and my own, to create a collective voice; from the position of us asking others to change their approach or practice towards young women with physical disabilities. The term 'You' is used in a collective sense to address both society and those involved in any way in supporting young women with disabilities.

You need to acknowledge us

You don't need to fix us

You need to be recognise us

You need to hear us

You must give us autonomy

You need to guide us

You have to connect us

You must teach us about us

You need to give us space

You have to give us our information

You need to allow us to be angry

You should allow us to complain

You should make sure we know that we count

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Appendix 1



Downloaded: 11/11/2018

Approved: 18/06/2018

Emily Allsopp

Registration number: 160102453

School of Education

Programme: doctorate of educational and child psychology

Dear Emily

PROJECT TITLE: The stories of adolescence told by undergraduate women who identify as physically disabled: A Narrative Inquiry

APPLICATION: Reference Number 019681

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 18/06/2018 the above-named project was approved on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 019681 (dated 15/06/2018).
- Participant information sheet 1045329 version 3 (15/06/2018).
- Participant consent form 1045328 version 2 (15/06/2018).
- Participant consent form 1044979 version 2 (31/05/2018).

If during the course of the project you need to [deviate significantly from the above-approved documentation](#) please inform me since written approval will be required.

Yours sincerely



Ethics Administrator
School of Education

Appendix 2: Recruitment email

Subject: Do you identify as **female and physically disabled**? I would like to hear your story of adolescence!

Content of email:

Who?

Hello I am Emily Allsopp, a third year Trainee Educational Psychologist at the University of XXXX. I have Arthrogryposis, (a physical disability).

What?

If you are female and self-identify as physically disabled as I do, I would like to hear your stories of adolescence using a Narrative approach. I would like to interview you for approximately one hour (audio recorded) to hear your story and share mine. The interviews will be transcribed and used in my Doctoral Thesis (anonymously). They will take place at the Uni.

Why?

I hope that the results of the study can influence Educational Psychology practice when working with young women who identify as physically disabled, in terms of considering their well-being and identity alongside their physical needs.

Theory suggests that adolescence is a critical time in our identity development; this is why this is the focus area of the study. Disability research has indicated that being female and having a physical disability can impact our experiences and opportunities. Therefore, the aims of the study are these:

1. To hear and understand stories of adolescence from female undergraduate students who self-identify as physically disabled
2. To develop an understanding of the participants' identity formation during this time period through their stories about themselves
3. To experience and analyse, as a disabled researcher, the shared experiences through hearing the participants stories
4. For engagement in the research to have an emancipatory benefit for the participants through voicing their stories of adolescence and disability

When?

The interviews will take place between October and December 2018, this academic year. This will be followed up with a phone consultation in the new year to 'check back' with you regarding my analysis of your data, to ensure I've captured your story.

If you are interested in sharing your story, you can contact me, the lead researcher, Emily Allsopp at <mailto:> with any queries but please see the information sheet attached to this email.

Appendix 3: Consent form

Consent Form

Project contact details for further information:

[EMAIL](#) (Trainee Educational Psychologist and lead researcher)

Supervised BY EMAIL (School of Education, University of XXXXX)

<i>Please tick the appropriate boxes</i>	Yes	No
Taking Part in the Project		
I have read and understood the project information sheet dated 15/06/18 and/or the project has been fully explained to me. (If you will answer No to this question please do not proceed with this consent form until you are fully aware of what your participation in the project will mean.)	<input type="checkbox"/>	<input type="checkbox"/>
I have been given the opportunity to ask questions about the project.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the project. I understand that taking part in the project will include engaging in one narrative interview of approximately 1 hour, with the researcher, this will be audio recorded. A pseudonym will be given to me to protect my identity and the name of my institution will be changed and non-identifiable. I understand that the theme of the interview will be reflecting back on adolescence and disability.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my taking part is voluntary and that I can withdraw from the study at any time/before December 2018 I do not have to give any reasons for why I no longer want to take part and there will be no adverse consequences if I choose to withdraw.	<input type="checkbox"/>	<input type="checkbox"/>
How my information will be used during and after the project		
I understand my personal details such as name, phone number, address and email address etc. will not be revealed to people outside the project.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs unless I specifically request this.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that other authorised researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	<input type="checkbox"/>	<input type="checkbox"/>
I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.	<input type="checkbox"/>	<input type="checkbox"/>
I give permission for the analysis of the transcription in the researcher' s doctoral thesis (to include direct verbatim quotes) that I provide to be deposited in White Rose Framework/University	<input type="checkbox"/>	<input type="checkbox"/>

of XXXXX Library so it can be used for future research and learning		
So that the information you provide can be used legally by the researchers		
I agree to assign the copyright I hold in any materials generated as part of this project to The University of XXXX.	<input type="checkbox"/>	<input type="checkbox"/>

Name of participant [printed]

Signature

Date

Name of Researcher [printed]

Signature

Date

Appendix 4: Information sheet

You have been invited to take part in a research topic here at the University of XXXXX for my Doctoral Thesis.

What is the research about?

Thank you for your interest in my research. I am a researcher and Trainee Educational Psychologist with a physical disability. If you are female and self-identify as physically disabled as I do, I would like to hear your stories of adolescence.

Theory suggests that adolescence is a critical time in our identity development; this is why this is the focus area of the study. Disability research has indicated that being female and having a physical disability can impact our experiences and opportunities. Therefore, the aims of the study are these:

1. To hear and understand stories of adolescence from female undergraduate students who self-identify as physically disabled
2. To develop an understanding of the participants' identity formation during this time period through their stories about themselves
3. To experience and analyse, as a disabled researcher, the shared experiences through hearing the participants stories
4. For engagement in the research to have an emancipatory benefit for the participants through voicing their stories of adolescence and disability

I hope that the results of the study can influence Educational Psychology practice when working with young people who have physical disabilities, in terms of considering their well-being alongside their physical needs.

Your participation in the research is entirely voluntary, and you may withdraw at any time without giving a reason. You may also request that any information/recordings be destroyed at any time. All information you give will be kept strictly confidential.

You can contact me, the lead researcher and Trainee Educational Psychologist, Emily Allsopp [EMAIL](#) if there is anything that is not clear or if you would like more information. Please read the following information to help you decide whether or not you wish to take part in this research.

What will I need to do as a participant?

You'll need to engage in a face to face interview, with myself for approximately 1 hour. This will take place at the university in a private room (such as a group room in the IC) the room will be fully accessible. I will be asking you Narrative questions about your adolescence and your disability which will prompt you to tell your story. These are not structured and will relate to your experiences, told from your point of view. If it is helpful for you I can share my experiences with you, much like a in a conversation, feel free to ask me questions. The interview will be audio recorded and I will be transcribing the audio data.

You will be able to keep a copy of this information sheet and you should indicate your agreement to the related consent form. You can still withdraw at any time, you do not have to give a reason.

What will be the implications and or benefits for me as a participant?

Participating in the research will mean discussing potentially sensitive information relating to your adolescence and disability (e.g. family dynamics, relationships, upsetting events in school) but this will depend on what you choose to share with me. I will not ask direct questions about these topics. I hope that the research will give you the opportunity to have your voice as a, physically disabled women heard. Engaging in a shared experience with myself as a disabled research could be beneficial for you. Other than this, the potential physical and/or psychological harm or distress will be expected to be the same as any experience in everyday life. However, should anything arise in the interview that is upsetting for you and you require support, I will sign post you to well-being and support services available at the university (link below).

[WEBSITE](#)

Will my information be kept confidential?

Yes. I will have your name, due to the consent process but you will be given a pseudonym for all other references to your interview, such as the transcript and in my thesis. All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any way. Your institution, or previous institutions, will also not be identified or identifiable. Any data collected about you in the interview will be securely stored in a password protected file on my personal computer – only accessed by myself.

What will happen to the results of the research project?

Results of the research will be anonymously transcribed and analysed using a research method called narrative analysis. This will be part of my thesis. You or your institution will not be identified in any report or publication. A copy of the final report produced for the research will be sent to all the institutions that participated on the research.

Who is organising the research?

I am organising the research as lead researcher, Emily Allsopp (Trainee Educational Psychologist on the DEdCPsy course) and I will be supervised throughout the process by my Research Supervisor XXXXX (University of XXXX)

Who has ethically reviewed the project?

The project has been ethically approved by the University of XXXX. The University of XXXX's Research Ethics Committee monitors the application and delivery of the University's Ethics Review Procedure across the University.

What if something goes wrong?

If you have any complains about the project in the first instance you can contact me at EMAIL or my supervisor, Dr XXXX at EMAIL

If you feel your complaint has not been handled to your satisfaction you can contact the University of XXXX's registrar and secretary to take your complaint further

Contacts for further information

Emily Allsopp, Trainee Educational Psychologist, University of xxxx, UK. Email: EMAIL phone number:+44 (0)xxxxxxx

Appendix 5: Transcription 1 (Alex)

1. First, here because you identify as disabled, female – we are going to discuss adolescence with regards to those two aspects. The one is to tell me about your teenage years?
2. Brrrrrrrrrrrr b aba ba ok, so I spent my teenage years living back in ‘my home country’ and I was going to a secondary school that was also my primary school so it ran all throughout primary to year 11
3. hm
4. and then I switch to another secondary school for my a levels
5. ok
- erm - so I tell you about my teenage years
6. My mum called them the cockroach phase haha that’s what I remember laughs which I really like now in retrospect cause I used to wear like really baggy black clothes erm
7. So did i
8. Yes
9. Just, I was in that rebellious phase yeah I remember having lots of arguments with my mum which now again now in retrospect It’s like really?! Hahah
10. Yes, not much, about not much?
11. Yes not very sensical, yes exactly!
12. I was quite, I think I still am quite feisty, but I was especially feisty when I was a Teenager
13. Yeah, what about in terms of your scoliosis....when did that start or...
14. (change in tone)
15. My back problems started when I was like 5, so since I was 5 I had them. Err yeah it was quite, a complete surprise, because basically I was falling a lot of the street
16. Oh ok
17. My mum was realising
18. yeah
19. I fell for nothing, like there was nothing on the floor and I would fall and she took me to the Drs and they did a scan and it showed that one bone on the leg was a bit twisted and they thought, oh that must be it!! But nobody bothered to check, like look a little bit up within the scan and look that my back was bended as well
20. Yeah, right
21. So when they noticed that, that’s when I started having to wear the corset (sic: back brace)
22. Did you wear that in you teens?
23. Yes, I wore it from when I was five to when I was 16
24. Ok, so in terms of – how do you reflect on that now?

25. It was absolute hell
26. Really?
27. It I think, now is when you realised, then you are not, when you don't have it in your life, because it was normal it was completely normal, since when I was five I don't remember before you are 5 or not that much
28. True, or not that much
29. Yes not so much. And also when I was five, when you start y1 so my whole educational experience up to year 11, I was wearing a corset in school, and it was in the same school
30. Yeah – same pupils, same teachers?
31. Same pupils, same teachers, same everybody
32. yeah
33. because it was also quite a small school
34. yeah
35. How do you think that – what do you think that meant for people's reaction to you if it was obvious?
36. It was very obvious yeah, because when I was younger I was like a twig , I was really really tiny because also as well as wearing the corset I would have to go swimming for 2 hrs every day so I literally looked like a pro athlete
37. Wow
38. Honestly I know, I WISH IT STAYED ha-ha but no
39. Ha-ha, swimming pro!
40. So I was like a twig and then you'd see like a massive thing coming out of my torso, so like my torso didn't match my legs and my shoulders up so it was, and would also walk 'does impression'
41. Ok so it effected that too?
42. Yeah movement loads
43. What was your experience, how do you feel you were viewed by others? In adolescence?
44. Like a weirdo I suppose, I got bullied a lot in school in general, especially that one, it changed a lot when I went to the a level school – cos it was a bigger school, nobody really knew me, like only my classmates, but they were more focused on other things I suppose
45. Yeah interesting, so how did that impact you, that change?
46. It was a massive relief basically, I changed schools because I wanted to do psychology in my a levels
47. Hm
48. And I couldn't do it in the smaller school because it didn't have them and when I moved I realised that I could, I was not so much focused on it if that makes sense, because like it was a big school I could go to the like, for example, one thing that was very hard in the

small school was going to the playground like normally during lunch times and break times I would stay in class or I would kind of hide – sounds awful but it's true

49. Ok

50. Because being in the playground is when everybody sees you and people will normally be playing football and things like that and I, I couldn't move very well you see

51. Yeah yeah that makes sense, restricted movement

52. So trying to get away from a ball...

53. Yeah that's yeah that's something that I experienced or having adult support throughout playtime which Well for me, I think impacted socialising

54. Socialising I imagine

55. Yeah yeah exactly, the time that you spend with friends was altered for me. Did you find that?

56. Not because of adults because I never had any adult support what so ever none like I – it was very much like, it wasn't talked about it wasn't, I don't want to say I was a paria because I didn't feel like that as a child but now thinking back to way the adults treated was very much like a hush hush type of thing – cause I had to wear the corset for 24 hours a day but for example if I was doing PE I was allowed to take it off and then have to put it back, so I would do that in like a cupboard, like where they kept the brooms and the...

57. Ha-ha

58. I am not joking it was

59. I am laughing more that like, what does that say...?

60. What does that do to you?

61. Yeah what does that say that you have to hide in a cupboard, to put that back on?

62. And do it alone as well, like when you are six and seven years old

63. That little?

64. YEAH! And it was a massive thing like a massive plastic thing that would go to your shoulders to your hips

65. Yeah

66. You have to take it out and then put it back up

67. That's difficult

68. Its hard

69. Sound difficult;

70. So it was very much like yes hear you go into the cupboard get changed and come back out, it was like nobody wants to see you, acknowledge that its even

71. Yeah

72. ... a thing.

73. I dunno

74. Do, Sorry

75. Or that's how I think about it now, as I said, when I was younger I pffft completely
76. Yeah
77. Didn't process
78. Not phased? Did you consider yourself, identify yourself as having a disability or....
79. NO.
80. Or other term you wish to use, as a teenager?
81. Using terms a, no, I think its undeniable the fact that, especially when I was a teenager, I felt very much, different I would say that's how ive felt throughout my life, different
82. Hm
83. Cause the word disabled wasn't even mentioned. Ever. First of all I think because there wasn't the possibility of mentioning it because the laws in my country about disability are quite, more strict about disability than they are in England
84. Yeah
85. You need to be in a wheelchair you need to be blind or deaf to be considered disabled
86. Yeah
87. Know what I mean?
88. Yeah, that's interesting because what does that mean in terms of like feeling valid, for example, its interesting I just wonder what that would mean for your identity if you are not valid as a disabled person but also...
89. You are not normal either
90. You are living a disabled life...so to speak
91. Yeah, yeah I think its that middle ground of you know you are different but you're not different enough to get like help, if that makes sense
92. Yeah that really does make sense having a what id term a 'low level' physical disability that's not massively obvious erm did you ever consider, have that sort or argument with yourself when you were an adolescent, that sort of
93. What do you mean?
94. That sort of , I guess it's like when you're developing your identity was it just 'I'm different' or did you consider that I'm 'not this and not that' was it that black and white for you or...? That's not clear sorry
95. No don't worry, I'm trying to think....i think what I can tell you is when I was an adolescent, I know I was different because my family had always been very clear and very blunt with me about my problems
96. Yeah
97. It wasn't something that was spoken about a lot it was a matter of fact type of thing – so my mum would go so your back is a problem. We need to sort it out, if we cannot sort it out, this is what it means – it means that you're not going to be able to I dunno, go backpacking through Europe for example, or horse riding as a professional career

98. Ha-ha yeah

You know like my family would very much tell these are the things you cannot do because of your back, we need to accept it, what can we do – that's how they framed it

99. Yeah, what else can you do yeah? I wonder what your thoughts were about that as an adolescent, like you can't do x and you can't do y cause erm I think I had quite similar – I think to some degree id massively reject that and be like 'I will' and it creates a little bit of defiance but I also think I was quite scared as a result of that of trying different things

100. Hmm

101. But I don't know whether that's ...that happened to you? Or its just matter of fact?

102. I think it was very much matter of fact and very much accepting well that's it then I cannot like if mind you this is how my family has been though throughout my like, we

103. Hm

104. We have been very matter of fact type of family ha-ha does that make sense?

105. Yeah

106. We and so for me it was more of the kind of thing well if I need to go travelling I'll need a carry bag and it needs to be tiny and of like it's the little things like I only ever carry a small purse, like a child's bag ha-ha

107. Ha-ha

108. Because if its big it hurts my back, so you live to adapt I suppose

109. Yeah I like that

110. Without thinking about it that much

111. Yeah it just a similar thing, same thing with a bag I always carry a back pack because then I've got both of my hands free cause my left hands not good enough to have free if I've got a shoulder bag in my right hand, you just do it, I think it's its

112. It is an extra effort I think

113. Yes it is yeah

114. One thing I remember when I was a teenager, probably jealousy, if that, it sounds awful but it is true like jealousy of other teenager girls that could be going out with ...it sounds silly ha-ha... going out with a bag with their make only, I couldn't!! Like...

115. No it's not silly

116. Like if my hair looked messy well fuck you Raquel you know ha-ha

117. That's so interesting

118. Other people will have a brush in their bag

119. Yeah That's so interesting because, it comes down to what is important when you are a teenager, and those things when we were growing up, those things were important because I couldn't if I had my hair tied back and it fell out I couldn't put it back again and I had a similar thing of like well I'll just look a state that and that, I felt that that

120. Yeah

121. Affected my self-esteem at the time and not sure if you felt...

122. Yeah self-esteem, that was a massive issue when I was a teenager, especially like,
123. Same
124. Clothes like I have to be very careful what type of clothes I wear because for example if I wear anything that cuts the upper waist you can see the curve quite a lot of if I put something that cuts right on my waist you can see the imbalance in the hips
125. Yeah
126. So like those type of things and my mum was really good at that cause she was the one buying clothes when I was a teenager and she would always buy the clothes that would make it less obvious
127. That's interesting in itself isn't it...
128. Yeah cause I had to hide it, I had to hide it
129. Yeah
130. And I...I still feel like that to this day I think
131. You do, I was going to ask you – I felt similarly about my shoulder, not so much my hands which is interesting, but then erm I guess what you going to cover it with?! Ha-ha you can't wear gloves like just one glove
132. Ha-ha
133. like all day but more from my shoulder because, anything I wore bras had to wear a little adapted bra strap because bra straps would constantly fall off, t-shirts were always down on one side, and it sounds very very.... like it's a t shirt!! Now like at this age I'm like do I really, it's a t shirt it's a shoulder it does it really matter? But that's been a massive process, where as a teenager I thought it was disgusting
134. Yeah
135. I thought I looked disgusting, daily...which is really sad
136. Yeah and even with romantic relationships, I remember I was this is going to sound really bad on the recording but I was a little bit of a slut
137. Ha-ha
138. Not sexually mind you,
139. A flirt maybe?
140. Yeah
141. Yeah
142. Ah because I think I was so looking to compensate for how I view myself as disgusting that's not worthy of ever having a partner cause who is gonna want me naked like
143. I had exactly the same, I had no experience with boys throughout my entire teenage years until 19 and that was, I did different to you I completely hid, well like they won't fancy me anyway so just cut that out as an option for me there was a – I now reflecting I put that down to lack of role model, personally like
144. Hm yeah
145. Fff Where do you see woman with a physical disability being like lusted after?

146. No, no you don't now!
147. Are we joking? Ha-ha
148. You don't know Yeah ha-ha
149. Yeah where was that representation? Where was that representation in school...I had no....the only recollection I've got of sex ed. is in year 9 was putting a condom on a model with one hand cause id had surgery so...
150. We put it on a banana not a model
151. Everybody else had banana! Why did my school have these models, so bizarre, haha
152. Ha-ha
153. but um yeah that's my that's what I remember of my sex education like a couple of videos to discuss like gay relationship and different forms of sex I think and that was it but no body broached that with me
154. hm
155. Which I felt it's an important stage of your teenage years that finding out
156. An important conversation
157. Yeah
158. Not even your parents?
159. Not really they're like massive prudes, I think my mum once said to me be careful and that's about it but erm yeah its interesting that you viewed yourself like that
160. Have you or how have you worked through that into adulthood like where you are now? Do you think?
161. I still don't like show casing my back definitely
162. Yeah
163. Especially, it's just because it's not symmetric if that makes sense like if you depends on how clothes I wear you can really see that it's not symmetric and I really don't like that
164. Yeah
165. In terms of relationships I was very lucky to find a partner that was really not bothered whatsoever and he tells me that I don't fucking care and i
166. Same yeah
167. Love you for who you are and
168. Yeah same here
169. I think that's what really has allowed me to stop thinking about myself as disgusting in the physical sense,
170. Yeah
171. It has been through him rather than through me
172. Yeah, isn't that interesting as well that those standards that we hold for ourselves in terms of beauty standards are like you're not symmetrical – no one's symmetrical number 1 but that's what for me, that's what you've seen in like magazines, TV, everything when we

were growing up the ideal was size 0 erm and that the big thing about having a thigh gap etc. and cause I couldn't exercise I was overweight and I think that I think THAT body image was so bad that actually I was more bothered about being fat

173. Yeah

174. Than I was about being a disabled

175. Which is quite interesting...

176. Which had a way bigger impact on my life in terms of ability which just says everything about what you're made to think you should be but do you think, I was going to ask, how do you think it would have been as a boy?

177. Hoooo I've never thought about that before

178. It's just because some of this refers to feminist stuff and some of the literature describes it as – having a disability and being female as a double disadvantage

179. I believe that actually, I think that if I was a boy I wouldn't have been that bothered, women...like if you look at media how many more models of women accepting differences in men do you find, beauty and the beast, the Simpsons, look at the body differences

180. Oh my god that's a revelation

181. So true

182. It's always like an average man with like a really fit (sic. Attractive) woman

183. And the disgusting fat husband yeah, and that's ok

184. Ha-ha

185. That's really true – or the husband is really really flawed e.g. Homer Simpson, he's overweight he's an alcoholic, he makes mistakes all the time, he doesn't look after the kids properly – just a character but that's what we have been shown growing up

186. Yeah

187. That is ok cause he has a pretty wife, so he is validated by having a pretty wife

188. Or its showing the idea that no matter how floored you are you are still worthy of love of a pretty woman

189. Yeah

190. This is now me in adulthood thinking about it

191. Absolutely

192. Reflecting Back

193. But if I was a teenage I don't think I'd be that bothered because also women I think you look at ALL the parts of your body scrutinise all the parts where as men just focus on being muscular – arms chest etc.

194. Yeah

195. Also I think, particularly in your teenage years there's a tendency to – you could be the worst person in the world in secondary but if you were a fit girl it didn't matter, whereas if you were a boy you could be funny, laddie, clever, nerdy etc. well if you're not fit your nothing (girls) was the impression in secondary school that I got

196. Yeah
197. For me it is different, for me I looked like a model, very fit
198. You had that experience of having the perfect body...
199. Yeah and still being thought as disgusting, because of my impairment
200. But all of our perception is wrong, in my view, it's through media, other people, lack of acceptance lack of representation, Cause did you know any other people?
201. No never, no and it's interesting because of my back I had to go to a specialist regularly and there were other young people in the room the same
202. I remember that too
203. I think it's interesting how I never started a conversation with any of them ever
204. No neither did I, I did have a sense of like oh they're like me, they have something I have – but no communication because it probably needed to be facilitated
205. By adults yeah
206. Cause ironically I felt awkward doing that, just approaching, and still do now in that situation
207. Who probably shared your experience?
208. Yeah
209. I dunno if you have that if you come across someone else with an impairment or? Cause I feel they're 'like me'
210. Well I think it's one of the reasons I wanted to work with children with SEN because my life in school was hell, was horrible, not only cause of my back but also I had difficulties reading and writing but my back was also very obvious and that's one of the things that, I don't want people to go through the same thing and I suppose that's why – yeah I do I get, when I work with children I think 'I know where you're coming from'
211. Yeah you feel like saying that to everyone – I know what it's like to be the one that's pulled out of class, missing lessons cause you've got this and that appointment, looked at talked about catered for all the time
212. Or used as an example...I remember for me with the bullying it was bad but I was outspoken, I spoke back, it looked like I was defending myself
213. Not a victim?
214. Well I was but not seen as one cause I would stick up for myself and respond but in a very self-deprecating way- so they'd say, you are disgusting or whatever I'd say yes I know – I know, don't you see, do you want to touch it? And that would shock them and they'd stop – but for me that's not an easy thing to do
215. No its not, yeah I remember I only one incident of a girl repeatedly calling me a spastic, in a 'jokey' way but only me... no one else, - my parents said to me if she's saying that and you don't like it you need to tell her to stop and I did and I was only in Y7 but its interesting cause I had a couple of other comments through school and past that age, particularly post-surgery, I didn't say a thing I never confronted anyone else after that one thing even though it worked
216. So why didn't you?

217. I don't know, confidence, I suppose that I didn't – maybe I believed what they were saying or yeah – a little bit like meh – which is not right is it, when someone's commenting on your appearance...cause like now if anyone commented id bite their head off
218. Yeah I would but I wouldn't feel bad about it
219. You wouldn't self-deprecate?
220. No exactly
221. Its them it's their issue
222. I wouldn't internalise what they said cause as a teenager I did I would snap back at them but I was commended for that, mum complained about it me coming home crying etc. and the head teacher said well she deals with it so well but you wouldn't
223. That's not ok....You were a child
224. I was able to snap back but the comments I used were self-deprecating and that's what I would internalise but it wasn't seen like that
225. It's not a solution, I remember often getting comments like oh she's really determined etc. actually that's a constant internal struggle I was extremely anxious such as when asked to read out in class, centre of attention, I didn't even want to look at myself I didn't want the whole class looking at me and it was never ever raised in 5 years of sec ed, and that it's almost like faux recognition like oh isn't she good, quite doesn't let it get her down etc. etc. and you think yeah but that was just a mask, that wasn't the case at all but it was never explored by an adult in school at all so
226. Was that because they didn't even ask?
227. No one asked me how I was in 5 years of sec ed., in terms of work learning etc. they did – and people would ask about my surgery but just in an interested way – but no empathy, that was really lacking, like – which is an interesting thing to say now that I'm into disability studies and rights etc., I don't want to be pitied but I think when you're developing...
228. I don't think it's about pity I totally disagree with that I think it's about recognition, what we were saying earlier about no fucking role models and no acknowledgement that it's even a thing, like I was put in a cupboard course people didn't want to look at me
229. Yeah
230. It's about recognition not about feeling pity – sorry I get very angry now looking back at it
231. It does, it makes you angry and it's a difficult subject because there's nothing you can do about it now
232. And you didn't know, it didn't even process when you are a teenager or child, you take it as normal because that's what adults tell you to do
233. And there's a narrative of sec ed. is hard, being a teen is hard, early relationships are hard ...so you've got it in your mind that this is supposed to be shit, but that's not true, not everyone had the experiences of sec ed. that we had
234. No
235. Some people flew through lots of friends, healthy, I feel like my situation is very much viewed as a moody teenager, emo, like quiet oh she's shy etc. all these constructs and as an adult none of these are true, what so ever, they weren't true before – we skip to being 13

(surgery) and all these things about me were true for that set time but went and are no longer true – so were they true? That narrative still exists now, talking to primary school SENCOS worrying about sec ed. cause they'll get bullied, they'll get comments, they're Autistic and flap or they look different

236. For me when I hear those things it makes my blood boil so much I can't even describe, how much the word coping makes me angry, it's a self-fulfilling prophecy we are saying because they are have something wrong with them they are not going to be able to deal with normality, of secondary, and there is nothing we can do about it because they are weird

237. Yeah

238. I was just thinking earlier about what you said - others that fly by – I remember a friend, as a teenager, good at school little heavy so now thinking more it want perfect for her either

239. Not in those times no, most weren't heavy

240. I saw her as the perfect girl, good friends, got a long but looking back I think I was massively jealous, nothing physical wrong, good at school, good at reading and writing – she was very much everything that I wasn't and I remember thinking how fucking lucky she is she has everything,, no problems, her life has been easy – probably not true

241. No none is and teens are finding out phase for all

242. I remember that and I knew a lot that there was something not quite right,

243. Yeah, that's interesting your perception – you didn't think about her weight – what does that say about our perceptions of us, that you didn't even register that

244. No

245. Yet you were hyperaware of others perception of you, like of Raquel's so buff she's built and slim, etc. etc. – did any of these cross your mind? Or about your outspoken natures? Others might have wanted that – I didn't have any positive representations of myself

246. Me neither

247. Other than being good at x y and x – creative for example. I had none

248. I think as a teen you don't see the positives

249. But now maybe it's different because now, I dunno if you do but I follow quite a lot of body positive pages, disability, chronic illness etc. –

250. I think people massively underestimate the positive impact social media can have – if I was a parent now of a kid with a disability like me – which is a possibility as well like that's another things its genetic so my child might have this so that's another thing that you think about when you're a teenager

251. Yes same – so did I bit early

252. But nowadays, the min my child is old enough, I would be the one finding disabled examples online for my child and those who advocate they will be on my child's feed – that's a way of seeing that without them being in your neighbourhood

253. Yeah mines 1/3000 or something weirdly there was a child down the street from me effected in the same way, born in the same year, but then my disability was very much talked about – you have AMC, you have a disability throughout, whereas I suppose you

weren't – so I went to meet ups, children's hospital events etc. but then they were kids as well – I needed an adult role model, they were the things I was worrying about, married baby, job, car, Uni

254. And you could have been reassured so easily by that

255. Yeah exactly and the sad thing is you shouldn't have to be 26 27 starting this specific career

256. And suffering anxiety – about driving for example

257. Yeah exactly, like you shouldn't be waiting 'til this age and then coincidentally beginning a course which is largely about disability to find out about disability rights, studies, to find out about how much this has impacted you when you grew up like this is not ok – this should be taught – what about the other people that are disabled and never get access to info about their rights etc.

258. This is about normality – we (society) have such a strong sense of normality and we want to preserve it so much anything that goes out of normality we better not talk about it we better not teach it even, it's like diversity, e.g. why don't we teach that? How much immigration do you have here like 13% or something?

259. It isn't done well if at all

260. I think its parallel with all the other aspects that fall out of white straight society, binary

261. Class even, for me that's important, even the literature in disability is so male, white middle class males there are much fewer articles by disabled feminist writers – there is a lack of representation in research - What – how do you feel about that term now? Disability? Or impairment etc.?

262. I think there is two things to this, I probably don't and not because that isn't true but probably because of the stigma – I don't because of the perception I still have in my head from growing up of what a disabled person is – which is someone in a wheelchair

263. Its everyone else too ha-ha

264. If I think rationally, yes, I would be classified by that BUT if you ask me based on belief I'd say no cause it was never discussed until I came here and actually, like when you look at driving – my future, it's a topic I don't like discussing or thinking bout but I know I'll be worse with age and I may need a chair – at that point I'd probably be considered disabled- so its...

265. Yeah, did you worry about that when you were a teen?

266. Massively as a teen yeah, nobody tells you either, for me there was always the possibility of the op looming, I'm border line being able to have it

267. And did you have any influence over that decision? How old?

268. Yes definitely, I was 15 it was around the time that my bones set – I was taking off the corset etc. – my family always – well maybe not now I think – but they tried to give me a choice or some control – but not 100% of course nobody asked me 'Alex do you want to wear a corset for 24 hours when you are five years old' like....?! And this is something that looking back it amazes me how ok I was with it – never complained, disagreed no fuss over the pain – my mum said I did at first but then I got over it and was fine

269. It is interesting that you just

270. Nowadays if someone made me do that, now I'd say fuck you

271. Of course! Why would I do that, I'd rather be comfortable and have a different back! But that's not...
272. Cause actually it didn't help, so it was for nothing I fucked my childhood and it ended up the same
273. It comes back to that normality you mentioned
274. Yeah course my parents wanted my back to be normal
275. Yeah and mine wanted my hands to be normal, yeah surgery at 2.5 and 3 years old, 13 was the one where I consented, but one was to correct an injury whereas one was cosmetic
276. Well my surgery would've been cosmetic it wouldn't improve my life the opposite it would restrict my function
277. Yeah I had that offered at a young age for them to fix my hands straight, even then I thought it was stupid – just to look normal
278. How do you offer that to an 8 year old?
279. Well you were smart; imagine an 8 year old who had been suffering bullying for years would you have said yes?
280. Well yeah exactly – it's very dangerous because your body and choices aren't your own – which is something else – what was the relationship between you and your body?
281. I hated it, I wanted to change it, absolutely
282. But yet you didn't consent
283. I was this close, you know what stopped me, it would've fused my lower and upper back completely – no bending or twisting of the torso, that's severely impacted – what made me not was looking online for I found a dancer with scoliosis, had the op at 20 and because of it she couldn't dance and she ended up reversing it at 30 something, and that this was the best decision she made, accepting her back and her movement and not wanting to change it
284. Did that impact you in any other way?
285. I suppose it did help me to think well it's my back and feel ok about it not embarrassed...I'm not saying I felt 100% with it at that age but looking back it really did start the path..
286. That's interesting I had a similar moment, in an art class, 1st day of sixth form, new school different peers etc. moved on fresh start, I'm going to recreate myself, so 1st session day 1 the task was to draw hands – and they had all of my paper work so you'd think they'd know- but it turned out to be one of the best things for me cause I got upset and the teacher took me to one side and was like we have messed up here – and it was one of the first times an adult had ever admitted fault to me, it was them that hadn't considered me, when he apologised, a new one to me too as a child – he said are your hands not objects, are they not hands, the purpose are to draw them – so do that? That was so important because what he said there was its fine to have your hands – my parents did but its unconditional – he was a very, people hated him, snarky, strict, people would berate him, he was my favourite teacher from them on – that validation – that was a turning point for me
287. I think that matter of fact thing works really well, my fondest memories of my mum and helped a lot was – I was going to the beach and had a bikini and my back was on show and I dint want to wear it getting upset etc. and my mum took my put me in front of a mirror she Was like look at it, this is your body you get 1, if we can fix it we will, if not its your body

is it going to stop you from getting on with your life? If it is that is stupid. She was so matter of fact but it really helped me

288. It is validation

289. Yes and that fact that there are things that you cannot change in the world and yeah if you have the short straw in this society cause you're not seen as normal but who the fuck cares, nobody's bothered and no one is going to help you if you don't help yourself I think

290. Yeah that is so true, that's a really good message, I'm thankful I got that from my parents other than them being over cautious about me trying new things which transferred to me – it lead me to be anxious – they were like no you do, like my sister- my story was a lot like her story but with a lot more worry e.g. they worried more about me moving to uni than my sister, she's able but more confident and outspoken than me – it's that worry in the family because of you, I wonder what that means for identity?

291. I didn't get that – I was an only child, that also, and my parents was huge proponent of – I want you to be able to try everything so you learn what you like and don't like so she'd send me off to England to learn English – I went skiing with a friend I didn't really like; and every month of my teens, before that, I would be sent to summer camps alone, it was great I loved it, nobody knew me I was very social, I was very good at making friends just not keeping them – so I think my parents wanted cause I was having such a hard time with my peers they thought she needs to socialise without the horribleness. And it really helped.

292. And nothing like that occurred? You still had the brace looked the same,....?

293. I never thought about it!

294. Last question is how have you, found sharing experienced with a disabled woman?

295. I think it has been amazing, when I met you it has helped me think way more about things I never thought about that are important e.g. earlier, never complaining or questioning, no acknowledgement that I'm disabled, until I met you and we started talking about it

296. It's a long time isn't it, 26 years to be like, no actually it is quite difficult, as much as I want to be very feminist and pro-disability and say we can do anything! It is harder, life's harder but that's ok because other things in life are ok, good profession etc.

297. For me especially, the acknowledgement and the anxieties you had growing up for example having children, I never spoke about that with my mum ever, yeah or talking about being old and what happens if I get worse all these things

298. Yes well I have a vulnerability to arthritis and the surgery on my knee could fail past 30 – that's next year – there's that timeline others don't have so getting to discuss it with someone who gets it, gets the time pressure, like having a baby – there is on us, for age, ability, pick up the baby etc. since my friends had kids its played on my mind, the physical effort – that shared experience is helpful – imagine if we had gone to school together

299. Exactly or there had been adult role models, teacher, TAs and even now I don't know anyone that has scoliosis and is like 50, are they ok?! Are they, how's things? It sounds silly but it's always at the back of your mind, a constant, if I talk about things with my BF, he's useless, if it's about my worries about this he freezes – he can't relate

300. I had the same thing with mine, about travelling he said about doing that when we retire and I was like well if I can..., I might have sticks, chair I don't know... he just said you'll probably be fine but it's like you don't know that – they're never going to fully get that – as much as he's considerate and caring and gets that, even with my thesis I've heard him mention ableism etc. – but I can't wait and people tend to go 'oh but you'll be fine look how

you cope with it now' – but I'm 28! – My parents and friends have said things like that it's like how do you know? I might not! I had friends say 'you're not really disabled are you..?'

301. Well are you surprised I didn't identify with it, people say that stuff all the time

302. It's also that thing of shut about that thing I am awkward about shut up about that I'm uncomfortable, is the subtext – I can't think of you as disabled cause then I'd have a disabled friend and what does that make me? I can't know that for sure but that person was very image conscious

303. I don't think they even think it...it's not a ...its subconscious the same my parents, you're so amazing with what you've overcome, with your back, very nice but it hasn't disappeared, its not gone

304. Also being determined all the time and having to try is hard and tiring, and they set up this expectation, as much as they're positive, it sets the bar high for feeling like that all the time so you feel like you can't have your, 'why me' days etc. cause someone's set an idea up that you're resilient etc. and you think well I can't cause you set up

305. An image that I'm super strong? Yes completely

306. You can't be like, no I'd rather have normal hands – people would go oh don't say that they'd think you were negative and complaining,

307. I think we are very much allowed to complain –

308. But isn't it easier in this situation?

309. but it's easier in front of someone that understands

Appendix 6: Alex's I Poem

Alex's I Poem

1. The beginning:

*I spent my teenage years in
I was going to a secondary
I switched to another secondary
I'll tell you about my teenage years
I remember
I really like, now
I used to wear those baggy clothes
I was in that rebellious phase
I remember lots of arguments
I was quite
I still am quite feisty
I was especially feisty*

2. Diagnosis

*I was like 5
I was falling a lot
I fell for nothing
I started having to wear a corset (back brace)
I wore it from 5 to 16
I think now is when you realise when it's not in your life*

3. In school

*I was wearing the corset in school
I was like a twig
I was really really tiny*

I would have to go swimming
I literally looked like a pro athlete
I wish it stayed haha
I was like a twig
I suppose
I got bullied a lot
I went to
I suppose
I changed schools
I wanted to do Psychology
I couldn't do it in the smaller school
I moved
I realised I could
I was not so much focused on it
Before the move
I would stay in class
I would kind of hide
I couldn't
I couldn't move well you see
I imagine
I never had any adult support
I don't want to say I was a pariah
I didn't feel like that as a child
I had to wear the corset for 24 hours a day
I was doing PE
I was allowed to take it off
I would do that in a cupboard
I am not joking

I dunno

4. Having a disability:

I think it is undeniable

I was a teenager

I felt very much different

I would say that's how I've felt throughout my entire life

I think because there wasn't the possibility of mentioning it

I think it's that middle ground

I'm trying to think

I think what I can tell you

I know I was different because my family had always been clear

I think it was very matter of fact

I cannot

I'll need

I only ever carry a small bag like a child's

I remember when I was a teenager being jealous

I couldn't

5. Self-esteem

I have to be very careful what type of clothes I wear

I wear anything that cuts

I put

I was a teenager and she would always buy clothes that made it less obvious

I HAD TO HIDE IT, I HAD TO HIDE IT

I still feel like that to this day

6. Relationships

I remember I was a little bit of a slut (Flirt)
I think I was looking to compensate
I viewed myself as disgusting, not worthy
I still don't like showcasing my back
I wear, you can see that it's not symmetrical
I really don't like that
I was very lucky to find a partner
I think that's what really has allowed me to stop thinking about myself as disgusting

7. Gender

I've never thought about that before
I believe that actually
I think if I was a boy I wouldn't have been that bothered
I don't think I'd be bothered because women I think look at ALL parts of the body

8. Connecting

I looked like a model
I had to go to a specialist
I think it's interesting
I never started a conversation with any
I think it's one of the reasons I wanted to work with SEN kids
I had difficulties with reading and writing
I don't want people to go through the same thing
I suppose that's why
I do
I work with children
I think 'I know where you are coming from'

9. Reflecting back on bullying

I remember for me with the bullying

I was outspoken

I spoke back and it looked like I was defending myself

I was (a victim)

I would stick up for myself

I'd say 'yes I know, I know don't you see, do you want to touch?'

I would

I wouldn't feel bad about it

I wouldn't internalise what they said as I teen I did

I would snap back

I was commended for that

I was able to snap back

I used were self-deprecating

I would internalise but it wasn't seen like that

I don't think it's about pity

I totally disagree

I think it's about recognition

I was put in a cupboard, cause people didn't want to look at me

10. Affect

I get very angry now looking back

I hear those things it makes my blood boil

I can't even describe

I was just thinking of what you said earlier

I remember a friend as a teenager

I saw her as the perfect girl

I think I was massively jealous

I wasn't and I remember thinking how fucking lucky she is

I remember that

I knew a lot that there was something not quite right

I think as a teen you don't see positives

I think people massively underestimate the positive impact Social Media can have

11. Looking forward

I would be the one finding disabled examples online for my child

I think it is parallel with all the other aspects that fall out of white straight society, binary

12. Being disabled now

I think there are two things to this

I probably don't (identify)

I don't because of the perception I still have in my head

I think rationally

I would be classified

I'd say no it was never discussed until I came here (UK)

I don't like discussing or talking about

I know I'll be worse with age

I may need a chair

I'd probably be considered disabled

13. As a teen

I'm border line

I was 15 around the time my bones set

I was taking off the corset

I think

I was ok with it

*I never complained, disagreed
I did at first but I got over it and it was fine
I fucked my childhood and it ended up the same
I hated it*

14. Making changes to her body

*I wanted to change it absolutely
I was this close
I found a dancer with scoliosis
I suppose it did help me well, it's my back and feel ok about it
I'm not saying I felt 100% confident...but it really did start the path
I think that matter of fact thing works well
I was going to the beach
I didn't want to wear it getting upset etc.
I didn't get that
I was an only child
I went skiing with a friend I didn't really like
I would be sent to summer camps alone
I loved it, nobody knew me
I was very social
I was very good at making friends just not keeping them
I think my parents wanted cause I was having such a hard time with my peers
I never thought about it!*

15. On engaging in the process

*I think it has been amazing
I met you it has helped me think way more
I never thought about that are important*

I met you and we started talking about it

I never spoke about that with my mum ever

I don't know anyone that has scoliosis and is like 50, are they ok?!

I talk about

I didn't identify with it

I don't think they even think it...it's not a ...it's subconscious

I'm super strong?

I think we are very much allowed to complain

Appendix 7: Transcription 2 (Sarah)

1. Would you like to start by telling me a little about your disability? Or any stories that come to mind re your
2. Yeah my disability is probably at the mild end so, I was born with my left foot deformed and so that sort of my toes were pointing the wrong way so I had surgery when I was really small and then surgery when I was 14 so I suppose, it's not a named disability but it effects my gait and how I walk and pain etc. and I'm also dyspraxic so that doesn't help but I think it is my whole left side, to some degree, it's not got a name
3. That's ok thanks
4. So you said you had surgery at 14 how was that given your age?
5. So I had that because my tendons were too tight, so if I fell id go straight over I couldn't catch myself, so I suppose I'd spent every PE lesson id fall over if I ran, id fall flat on my face, so I experienced a lot of bullying, I was quite pleased that it could be fixed I suppose, but then it was also quite strange, cause well I spent all of the summer holidays on crutches
6. That's rubbish
7. Yeah but then I suppose I felt very self-conscious about it going back to school, I didn't use my crutches which probably didn't help but I was just so self-conscious about the whole thing
8. Do you think there's something about the teenage years that you're so self-conscious
9. Yeah
10. So, you mentioned bullying do you mind if we speak about that?
11. Yeah that's fine so I suppose, it was just sort of fun to other people that I kept falling over, like if I kept like when you walk into people you can quickly move out of the way, I sort of wasn't able to move, if I moved id fall over I suppose it was funny to people rather than anything else
12. Yeah, what was your response to that at the time?
13. I didn't like it I suppose, well at that time I didn't know I had a PD as such that was what id grown up with and no one ever mentioned that that's what it actually IS – I suppose you could see that my foot looked different had scars on it etc. I guess cause I didn't know that that was what it was, it was a little confusing
14. Its interesting because as someone who has had that term attached, it was slightly different to me I had that term attached a rejected it completely – compared to then how do you feel about that term now?

15. Err well I suppose I don't actually have one, I feel a bit fraudulent, because its not well I don't know I can walk basically but not masses I suppose, not on concrete, if you go to the Drs they like 'hmmmm' or google it there's nothing, so technically I'm an amputee, but that's only, that's if I'm being very technical
16. I thought it was very interesting your email to respond to this study you said, about being mildly disabled and sort of 'counting' I found that really interesting like whether it counts or not is that something that....
17. Yeah
18. That you struggled with in your adolescence or?
19. Yeah I think so – I think I just felt different as I was growing up and that I just had to consider things more, it was almost like I found things harder, without being able to justify it in my own mind erm yeah
20. That rings a bell for me – who was involved in your life at the time, who would have known that you felt like that at the time?
21. I don't think anyone really, a couple of teachers, like there was a student teacher in PE and I fell over and everyone laughed, I must've looked very sad, I can remember her going and telling the other people not to do that so I think some people sort of picked up on it but no one explicitly knew
22. Just, the people that noticed its by chance isn't it that's something I experienced too, it was people who just clicked with and not with a broad understanding of oh she's disabled she must struggle a little bit it was just the odd person. Was that the most significant event in your teens, the surgery?
23. Yeah I think and also, going into adult shoes was quite significant for me, my left foot was very high and very wide so trying to find shoes, kids shoes obviously go up in widths and when you get to adults, I wasn't able to buy anything from the high street and it was sort of – I mean I'd normally struggled but I could say I'm a 6 H or whatever, that was a realisation a bit of a moment for me growing up as well, like I can't wear flip-flops for example, cause of my toes, and other shoes
24. I don't want to put words in your mouth, but for me things like that were just another barrier to doing what everyone else was doing
25. Yeah like fitting in and something, yeah it's something that seems so simple, people could be like oh year I'm going to Primark and they'd pick up a £2 pair of shoes sort whatever, I have to pay £100 for mine
26. Sounds like a story about fairness
27. Yeah it is unfairness, like everyone had converse at the time, I did have some but they didn't fit, now I still have them and I can't get my feet in a pair, it's just slightly depressing

28. Its just one thing that you could do without – so when did thing start to change with how you view yourself, then to now?
29. Erm...well I've...well at 19 I was diagnosed with dyspraxia and autism at 21 so I suppose it has all sort of merged into one, so I now understand a few more things but I think particularly the dyspraxia, the physical stuff, I knew I could never hold a pen and the walking etc. but having that mean that at least I can say to someone oh I'm dyspraxia, even if that's not quite the route cause but it's something people have heard of and is easier to explain than saying like the ins and outs of how I was born – like cause that's the only way I can explain it really
30. I had a similar experience but not for the same reason so I have something a condition called Arthrogyrosis, which no one has ever heard of
31. I've no idea what that is
32. So its erm basically I didn't have enough space in the womb so my joints didn't form properly so I have bent joints, lack of muscle some joints are fused, no muscle in this arm – shows hands – I struggle with hand writing dressing etc. so I experienced that as well like having to say oh it's this and then go it means that this this this , which now I don't mind at all but as a young person I think it's different – it means that now that label for you has been helpful?
33. It's just easier cause people know what that means and they just don't understand the other stuff, and there are also other people that have dyspraxia like I can't like I have extensively tried to google, but there obviously will be people who have the same birth deformities but I can't find them, like I've never met anybody who was born like that, I mean I have met people with similar like a short Achilles but not the same, I suppose id quite like to meet some people that are similar
34. Yeah that's something I experienced, I mean did you have any influencers at the time? People who were disabled or different?
35. I went to as private school so I suppose and it had lots of stairs in it as well and cause it was selective anyway there were lots of, there was one girl a few years below who had brittle bones and things and she ended dropping out in about year 9 cause of all the stairs and that, apart from that I was the ONLY one and I felt very much the only one. And especially, and I've never been really skinny either and I suppose that's really influenced it as well because, well in my head it's like well , this is very unPC, but if your skinny and physically disabled you can sort of get away with it
36. That was really true for me, I was much bigger in sec ed, and I felt like, couldn't I just have 1?!

37. And when you can't do things you can see people looking and thinking hmm that's just cause you're big like that really didn't, I still struggle with that now but particularly as an adolescent that was quite, it was an all-girls school as well so the pressure was awful, the pressure was just..... ffff it didn't help
38. I can't imagine and the relationship between girls in school seems, well not empowering,
39. Yeah picking out faults and stuff
40. How about friends?
41. Well I had a small group of friends, I always thought of us as the misfits but then I suppose maybe we weren't it was just a group of clever people who didn't really follow the fashion well not didn't just weren't alternative but not really into teenage girl stuff particularly
42. Yeah I'd probably describe a similar group myself, so moving on from that was there any other transition, sixth form or?
43. I went to the sixth form attached to my school, so no move but, there was a dress code so it was sort of smart casual that was different, but I was allowed to wear trainers which others weren't so but so I suppose I stood out a bit but people kind of knew by then, like oh that's cause of that and I was like yeah and I suppose a lot of people had left who were like....the trouble makers, yeah so suppose that was easier
44. So how would describe the person that you were at that time, in sixth form or throughout – I just wondered if – for me I changed quite considerably from sec ed to sixth form that was quite a key move for me, with different people and attitude and didn't know whether that was something you experienced?
45. Not particularly for me cause it was the same school and people, we could wear our own clothes and stuff but it didn't feel like a massive jump I suppose
46. What about outside of school, in terms of your disability?
47. I stopped playing sport, cause at 10-11 I used to quite a lot of clubs outside but up to adolescence my tendons got tighter so I became more unbalanced and stopped til the surgery then after the surgery I couldn't do much cause I was recovering, I did do stuff, I did guides and stuff, basically I dunno, nothing desperately notable, yeah
48. How about at home, if you don't mind me asking? Siblings
49. I have one sibling,
50. it was ok, I suppose I had some mental health issues but they weren't really related to this, so er but yeah if I said like my foot hurts that's like the only thing my parents would say right let's stop but if you said something else they'd be like ok you're fine....
51. Oh right so the physical side?

52. Yeah and like yeah mum tried to be supportive find shoes etc. they are supportive with it, but is suppose there's nothing they can do, I think that sort of hurts my parents, I think my mum feels blamed because it was a random thing but obviously...
53. Same here. It's really interesting, the dynamic, I had surgery at 13 so on crutches and in a chair for a while in high school and its funny that you had the similar experience and for me it was a trigger point for me and not being happy with my body
54. I felt that, if I think back, that's the point that Yeah bit of trigger
55. It's very coincidental. So how would you sort of describe yourself as an adolescent?
Post-surgery
56. Very shy, reserved and sort of, very anxious and it almost feels like that was, there's post-surgery depression that you can get I think maybe I got that or something, something just changed
57. I certainly experienced similar I think being off your feet and in for so long, that contributed for me
58. Yeah
59. Has there been a significant point where you reframed your view of being disabled?
60. I think getting the other diagnosis and applying for PIP has made me view myself differently because I've got quite a high, well highest care and normal mobility I suppose in my head I'm like well if I've got that then there clearly is something that's a bit different even if I sometimes I think of its mild and I dunno if that's cause of other people going 'oh it's not that bad' etc. so I suppose I think that's reframed it in my mind sort of but then a physio said to me the other week, well you wouldn't could yourself as physically disabled would you and I was a bit like, hmmm so I don't know I think its cause I can hide it quite easily where as if I was a wheelchair user you can't hide it but in most situations I can hide it so it's almost like an invisible physical disability that doesn't really exist in the world
61. Yeah it's fascinating, it's something I really relate to – I don't walk differently its only when people notice my hands that they can tell and there's pros to that isn't there, where you can hide it
62. Hide it yeah
63. But I think there are cons around maybe counting, like you said in your email?
64. I suppose for me it's like dyslexia and dyspraxia and all those ones, which are invisible but when it comes to invisible PD no one counts them as invisible, and so I think that's also like going through adolescence like having surgery that's when I realised that I was definitely different and I didn't like that and then it's still slowly, it's taken 10 years and it's still like

65. I'd say it's a really long process, for me it's taken til I was on this course just two years ago that I started learning about feminism and disability studies and social constructionism and I thought this is out of order... I...like I count as much as someone who is in a chair – I've had similar like a physio saying to my parents – at least she's not in a wheel chair, and a friend at school who thought they were being nice say which sticks in my mind, but you're not really disabled are you, they stick in your mind but – is there anything that's stayed with you?
66. Well I was a bit older but a few years ago I went to orthotics to get insoles and they wouldn't fit in my shoes obviously so they made them really thin and it turned out after that they'd basically made them too thin so I was basically walking on nothing but obvs I tried them for a bit and ended up on crutches and they thought I had arthritic sepsis or something but it turned out it was just these insoles but while I was on crutches, going on the tram in Nottingham, people were instantly like, they gave up their seat and I always think well if I just got some crutches...cause I have a disability pass but I don't feel I can ask someone I can move from their seat cause and I really struggle on the tram to stand and I just like oh...and also I feel like I'd be quicker on crutches walking, when it's a really bad pain day, it's just like oh if I bought some crutches... would it make it all better or would it be easier if it was something more visible, or
67. That really resonates with me, because I struggle to grip on the tram and the bus is even worse but I really feel that awkward, can I ask? Cause I just look normal so I don't tend to and struggle. I asked once and got a negative response and thought wow...it sort of stops you then, cause It was true, it's funny that these things effect you or the contradiction between the ability to be invisible but looking 'worse' might benefit us
68.
69. Do you have any other particular times that stick out for you for being really emotive?
70. There is one other, I was at a guide camp doing sports and there were two teams and I fell, and we came last because of me and the quip after of someone like 'oh we would've won if we didn't have her on our team' that's probably the only one but no I don't think there's anything else in particular.
71. That peer interaction. Did you have any additional help at that age or?
72. No nothing I think in PE, they didn't know anything until the surgery – they saw the scar and were like that's quite major surgery... I was like yeah ha-ha they didn't know
73. I wonder who that rests with
74. Well I suppose when I started at 11 it didn't really affect me. I suppose in PE they picked up that I was a bit clumsy I suppose

75. When did you receive your other diagnosis?
76. 19 and 21
77. First year of Uni? How was that for you?
78. I was quite pleased to get the dyspraxia one because I'd always had trouble with writing and PE etc. and it was always put down, to and then I always had difficulty reading something wasn't quite right that 'that couldn't explain and that was quite good as well and like to coordination.... Like I use my left hand to steady myself so even if I'd made the coordination work... I wasn't born that way it reassured me that I had something I could explain
79. How about if you had that diagnosis earlier?
80. I think it would've helped a lot, not just physically like with reading and things but yeah in PE it would've helped a lot for people to know I had a thing – cause people were quite nice to people when they knew they had something, like dyslexic or,.... but there was also a culture of oh your re just trying to get an advantage because it was a private school and people were quite competitive, and clever anyway, well you just want extra time in your exams...this or that
81. That's something, a dynamic I don't share in so sounds like a lot of pressure?
82. There was a lot of pressure to not be different, and to fit in yeah...
83. How did you respond to that?
84. I just went against...well not against it I just didn't go with it,
85. I was sort of similar, but an emo like wearing all black ha-ha
86. Ha-ha
87. Because, part of the research is linked to identity, how did you sort of 'find yourself' in that time? How did you think of yourself?
88. I think I didn't really understand it, I think that's being autistic, I didn't really get it, and I don't think I do know I suppose I just sort of wore jeans and t shirts I didn't quite, at that time it was all Hollister and A and F which I didn't have and wasn't desperate to have, I never thought I fitted in – I don't suppose I have a very strong identity... I was probably like the shy plane jane person
89. So how has that influenced you now that time?
90. Erm... I would say I'm still quite anxious form my school experiences, I don't think I've yet gotten to grips with where I fit in within the sort of PD world which I think hasn't helped from secondary school yeah I don't think I've quite...I don't know
91. That's ok
92. To what degree has your experiences in adolescence influenced what you do now?
PHD?

93. My 1st degree was in primary education but I didn't get QTS to become a teacher so I suppose my experience was that I like being quite interested in inclusion and disability and like my PhD is o Autism in higher education I suppose, my own experiences have definitely influenced how I perceive things,, I feel I'm quite open whereas I don't think society necessarily is sometimes so I think it's definitely shaped, what I do and think in that regard,
94. I think, I dunno if you're the same, but I wish I had had teaching around this in school
95. Yeah
96. It would've been helpful to hear those terms disability and inclusion etc. even feminism
97. I didn't know about critical disability studies until I came here, like autism as a social construct, and it's not necessarily that I agree with all the things its more, I hadn't appreciated that all these things exists
98. Yeah the different perspectives, just the one at the time, I think I became angry about that when I first learned about it, as a disabled person, that's my information, why did no one tell me about it, about my history and my community in school? It made he quite passionate about it hence my thesis, which is a stark difference to when I was a teen when I completely rejected the idea, like just ignore it
99. I think society has changed a lot as well and I always wonder whether if I was at school now, would I sort of know more and would it be more inclusive and things like that
100. I wonder that as well, especially with social media, its good and bad but there's so much awareness raising , cause I'm 29 this month and we didn't really have it may be a bit of Myspace, not as heavily as we do now
101. I don't remember twitter but Facebook was and MSN – certainly not like having access to all these disability campaigns on Facebook and videos of not horror stories but those kind of things didn't exist in the same way
102. No I don't either, now I actively look for accounts, I don't think I would've when I was younger
103. No me neither
104. So how would you have changed your experience? The typical magic wand question?
105. So I think I would have changed my parents view on what I had so mums a Dr, that probably didn't help anything I think I'd probably yeah if they had told me, cause all the way through it wasn't like it, it just was how it was – that was life end of and it still is in a way....but I suppose if I had then been comfortable and if I'd have known that it was a disability then I think that would've helped, I think in school there

- was no sort of, it might've been the school I was at, you learned about drugs alcohol, etc. but there was nothing about disability what so ever
106. Same here, there was sexuality, race etc. as there should be but it was like disability had been left off the list
107. Yeah nothing at all
108. I realise we haven't discussed, like being female, intersectionality, female and disabled, which the research covers...does that...?
109. Well I went to an all-girls school, we only saw boys on the train there wasn't, I wouldn't sent my kids to one, cause other people have been like oh gender and growing up etc. and I feel like that passed me by a bit, I went to a mixed sixth form, the local state one and coming to Uni as an 18 year old I was like there's boys here in lectures, they talk they're annoying ha-ha
110. Ha-ha
111. I suppose, but now I know about women being oppressed etc. that wasn't even talked about in school and they were going for women in science that was like the big topic at the time but nothing about oppression and that, feminism, now I find it quite difficult being a disabled woman
112. How so?
113. Well, it more just feels like I'm in several different minorities but then also like I'm white middle class, I'm also in lots of privileged positions so it also goes against each other and that...that is probably the biggest fraud I feel, by background private school and that, in that sense I'm not minoratised at all
114. I Woodlyn say I am either
115. Which I kind of feel like it clashes completely with the whole disability notion
116. The notion that disabled people maybe can't work or? Cant ...that sort of rhetoric
117. Yeah and that I might be able to, as a disabled person, with my parents back ground I might not be able to keep that going – keep it up because I'm disabled, even though there's the expectation that I will do XYZ and in secondary school I think I did feel that as well because mum was like don't talk about money and we were not like obviously there was a massive range and we were nowhere near the top, people had new cars and it was awful... but it was still felt a clash even at that age of things
118. Sounds like a story about guilt?
119. There's definitely guilt there...yeah
120. Cause obviously, second to white middle class man, white middle class woman is the second most privileged position to be in, particularly in our country and

then the other part of you is way down the list, the disabled part, judging by....the media social media newspapers benefits this.... it's a real clash

121. I think in adolescence, we could buy anything like new shoes etc. if I needed them if its help my foot, they could, buy it and so I sort of, it almost feels like the monetary side of disability hasn't quite affected me and therefore it's definitely clashed cause then I'm like am I disabled am I not disabled then growing up that was defiantly a thing that conflict
122. In the literature there's a distinction between – you have an impairment but you're disabled by society but then we are not...just like comfortable background, normal but ...it's something about feeling valid again isn't it – but like I don struggle but I also receive PIP and that makes me feel uneasy
123. I am very uneasy about that and well its more the piece of paper that I need but obviously I get the money as well, I almost feel like I'm not a stereotypically disabled person because at the moment I'm ok for money but the stereotype that you're not and you're not surviving
124. Yeah I mean it is an additional challenge statistically though, mainly because of stigma more than everything else probably then there's the gender pay gap but yeah the pip has always been like I've found I have conversations with myself like – well your life is more expensive that is a fact sometimes you need to get a taxi you drive a more expensive
125. You have to justify it
126. Yeah, no one else has asked me my mum n dads response was that you are entitled to it go for it, don't think of it, but I have to have those conversations with myself, the process was...
127. It was horrific yeah
128. He manhandled me, after the form and interview and I let that happen and I don't know why I let that happen, so demeaning
129. Final question, how have you found this process? Shared experience?
130. Quite good
131. Sorry you are on the spot, that questions came from the fact that I have not had much contact with other disabled people
132. I haven't really had any conversations with anyone else, cause its invisible, and I suppose unless you disclose you can't really tell
133. That's true, that's good, yeah has it been more or less comfortable with me being disabled?
134. More, I suppose its shared experience so, I'm more used to participating in Autism research where the researcher is not autistic at all, and erm, there are usually

several questions that allude to intellectual ability or you can't do X, Y, Z or ask you why, cause they don't have any personal experience at all, it's a bit easier cause you don't have to explain everything from 0

135. Do you have any questions for me – about disability or research?
136. Remind me of your research questions? What's the outcome?
137. It's a narrative study, to hear the stories of women with physical disabilities
138. Oh that's like mine, but autistic women in higher Ed.
139. Oh really? That's so similar, well thank you for taking part, the irony is that you are my only participant so far ha-ha
140. Ha-ha yes that says something, well usually I don't do research, and delete the emails but I didn't so obviously something clicked and it was something I wanted to talk about so that's interesting.

Appendix 8: Sarah's I Poem

1. An unsure introduction:

I was born with

I had surgery

I was

I was 14

I suppose

I'm also Dyspraxia

I think

I think

I feel

I couldn't

2. Bullying

I experienced a lot of bullying

I was pleased (to get it fixed)

I spent

I suppose

I felt

I didn't use my crutches

I was just so self-conscious

I kept falling

I kept

I suppose it was funny (to others)

I didn't like it

3. Grappling with her disability identity:

I didn't know I had a PD

I suppose

I guess I didn't know

I suppose I don't actually have one

I feel a bit fraudulent

I don't know

I can walk basically

I suppose

I'm an amputee

I'm being very technical

4. Reflecting back (on affect)

I think I just felt different

I was growing up

I just had to consider

I found things harder

5. Response of others

I don't think anyone (knew at the time)

I fell over

I must've looked very sad

I can remember

I think some people sort of picked up on it

6. The practical linked to the emotional

I wasn't able to buy from the high street

I normally struggled

I have to pay £100 for mine

I did have some

I still have them now

I can't

7. Change story

I was diagnosed with dyspraxia at 19 and Autism at 20

I now understand a few more things

I think

I knew I could never hold a pen

I can say to someone oh I'm Dyspraxic

I can explain it really

8. It's hard to find connection:

I can't, I've extensively tried

I can't find them

I've never met anyone who was born like that

I have met people with similar

I suppose I'd quite like to

9. Intersection

I went to a private school

I suppose

I was the only one

I felt very much the only one

I've never really been skinny

I suppose that's influenced it as well

I still struggle with that now

10. Relationships

*I had a small group of friends
I always thought of us as the misfits
I suppose maybe we weren't
I went to the sixth form attached to my school
I was allowed to wear trainers
I suppose I stood out a bit
I was like 'yeah?'
I suppose a lot of people had left who were trouble makers*

11. Outside of school

*I stopped playing sport
I used to go to a lot of clubs
I became more unbalanced
I couldn't do much because I was recovering
I did do stuff
I did guides and stuff
I dunno*

12. Family/Home

*I have one sibling
I suppose I had some mental health issues
I said like my foot hurts that's the only thing my parents would say right let's stop
I suppose there's nothing they can do
I think that sort of hurts my parents
I think my mum feels blamed*

13. Reframing

I felt that

I think back that's the point yeah the trigger (Surgery)
I think I got that (post-surgery depression) or something, something just changed
I think getting the other diagnosis
I've got quite a high, well highest care component
I suppose in my head
I'm like if I've got that then there is clearly something a bit different
I sometimes think of it as mild
I dunno if that's cause of other people
I suppose that's reframed it
I don't know
I think its cause I can hide it
I can hide it so it's almost like an invisible disability
I suppose for me
I think that's also like having surgery
I realised that I was definitely different
I didn't like that

14. being more socially able by being less physically able

I was a bit older
I went to orthotics
I was basically walking on nothing
I tried them for a bit and ended up on crutches
I was on crutches
I always think if I just got some crutches...
I have a disability pass
I don't feel like I can ask someone for a seat
I really struggle on the tram
I feel like I'd be quicker

14. Guides

I was at guide camp

I fell and we came last

I don't think there's anything else

15. Adult support

I think in PE they didn't know

I was like yeah ha-ha they didn't know

I suppose when I started at 11 it didn't

I suppose in PE they picked up

I was a bit clumsy

I suppose

16. Diagnosis

I was quite pleased to get the dyspraxia

I'd always had trouble

I always had difficulty reading

I used my left hand to steady myself

I wasn't born that way it reassured me

I had something I could explain

I think it would've helped a lot

I had a thing

17. Resistance

I just went against it

I just didn't go with it

18. Getting it

I think I didn't really understand it
I think it is being autistic
I didn't really get it
I don't think I do now
I suppose I just wore jeans and t-shirts
I didn't quite
I didn't have
I never thought I fitted in
I don't suppose I have a very strong identity
I was probably like the shy plane Jane

19. Now

I would say I'm still quite anxious now from my school experiences
I don't think I've yet gotten to grips with where I fit in the PD world
I think it hasn't helped
I don't think I've quite...I don't know

20. Career

I didn't get QTS
I suppose my experience
I like being quite interested in inclusion and disability
I suppose my own experiences have definitely influenced how I perceive things
I feel I'm quite open
I don't think society is
I think it's definitely shaped what I do and think
I hadn't heard of critical disability studies 'til I came here
I hadn't appreciated that all these things exist

*I think society has changed a lot
I always wonder whether if I was at school now
I sort of know more*

21. Magic Wand

*I think I would have changed my parents view on what I had
I think I'd probably yeah if they had told me
I suppose if I had then been comfortable
I think that would've helped
I think school there was no sort of*

22. Gender

*I went to an all-girls school
I wouldn't send my kids to one
I feel like that passed me by a bit
I went to a mixed 6th form
I was like there's boys in lectures
I know about women being oppressed that wasn't in school
I find it quite difficult being a disabled woman*

23. Class/Gender intersection

*I'm in several different minorities
I'm white middle class
I'm also in lots of privileged positions
I feel my background private school and that
I'm not minoritised at all
I kind of feel like it clashes
I might be able to*

I might not be able to keep that going
I'm disabled even though there's the expectation
I think I did feel that as well
I felt a clash even at that age, of things
I think in adolescence we could buy anything
I'm like am I disabled person am I not a disabled person
I am very uneasy about that
I get the money
I almost feel like I'm not a stereotypically disabled person
I'm ok for money
It was horrific yeah

24. This process

I haven't really had any
I suppose unless you disclose you can't really tell
I suppose its shared experience
I'm more used to Autism research
I don't do research and delete the emails
I didn't so obviously something clicked
I wanted to talk