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This is a Place for Talking –
An Exploration of the Transition to Adulthood for Young Women with
Epilepsy in a Residential Special College

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Doctor of Social Work

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April, 2013

I hereby declare that this thesis has not been and will not be submitted to another university for the award of any other degree.

Virginia Fenton

April, 2013

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This thesis is dedicated to the memory of one of my former students, Louise Webb (1986 – 2010). She was a remarkable and spirited young woman who played a significant part in inspiring and influencing the shape of this work.

University of Sussex

Virginia Kay Fenton

Doctor of Social Work

This is a Place for Talking –

**An Exploration of the Transition to Adulthood for Young Women with
Epilepsy in a Residential Special College**

Summary

What does it mean to be an adult? What makes a person an adult? How have the circumstances of the lives of the six young women in my study shaped their understanding and perceptions of adulthood? These are the research questions at the heart of this thesis. I wanted to know more about the experiences of the young women that I worked with as a carer at a residential centre for young people with epilepsy and the influences that their experiences have had on how they perceive the world.

This thesis begins with a puzzle in the form of fictional fieldnotes and concludes with an obligation. It charts the journey of the research from origins in a particular cultural setting to its conclusion as the beginning for the next stage, providing an opening chapter for the work that will grow from this study. The puzzle at the beginning of this thesis relates to the neurological functioning of a young woman, Evie (21). As soon as revealed, Evie is a fictional character whose story has been told to represent themes

from the research. Telling her story was also a way to use 'writing as a method of inquiry' (Richardson, 2003).

The methodological approach taken in this research sits within a phenomenological tradition by way of its modern guise as Interpretative Phenomenological Analysis (IPA) as developed primarily by Jonathan Smith, Paul Flowers and Michael Larkin. The use of this methodology reflects a concern with the meaning my participants take from their experiences (Smith et al. 2009). I focused on the transition to adulthood as this was the 'common phenomenon' that my participants seemed to hold as a central concern in their lives. Five themes emerged from the analysis:

- Alcohol = Adulthood
- Adulthood is - independence
- Adulthood is - domestic competence
- Adulthood is - a 'code of behaviour'
- Adulthood is - an achievement

The findings from the phenomenological analysis have been juxtaposed with an account of the research findings written as ethnographic fiction. 'Evie/I' is a story that includes reflections on the relationships I have had with young people in my care and the one which developed when I took on a researcher identity. It relates how knowledge of past histories shaped how I interpreted what the participants in my study revealed to me and the development of a reflexive stance as a researcher. It is my intention that the juxtaposition of these related but different accounts of the findings should enhance the reader's understanding of both.

Central to this thesis are Bourdieu's concepts of species of capital, habitus and field theory and they have been used as a theoretical framework. A conceptual model has been created to map the themes developed as they fit into the 'code of behaviour' my participants seem hold central to the achievement of adult status. The epilepsy centre where this research was conducted is a 'field' with certain characteristics. This has been considered in relation to the 'habitus' my participants have developed as young women

in this particular situation. Feminist theory has also influenced the way in which this research was conducted.

Research relating to people with epilepsy seldom includes the voices of those with the condition and qualitative research approaches are relatively scarce (Andermann, 2000). The young women in this study also have learning disabilities and this factor likewise lessens the likelihood that their views will be represented in the research literature (Walmsley, 2001; Atkinson, 2005). The rationale behind the research relates to the need to address this omission. The obligation that concludes this thesis concerns the need for further research that includes the perceptions and voices of young people such as those in my study.

Chapter One – Introduction - In the Absence of Loss

I do not know which to prefer,
The beauty of inflections
Or the beauty of innuendoes,
The blackbird whistling
Or just after.

Wallace Stevens

Evie

Fieldnote – 06/04/07

Evie (21) is a puzzle. We cannot work her out. Even the experts can't begin to understand what's happening in her head. Her neurological functioning is mysterious; she makes no sense at all. Sometimes I begin to wonder, when reading comments like these in her medical files, what is happening in Evie's mind when these events – imbalances between the inhibitory and excitatory neurotransmitter systems – have been taking place in her brain.

Fieldnote – 08/04/07

Evie presents her version of who she is as rather straight-forward. She describes herself as happy and friendly, although she admits she can be a 'worrier', due to 'all that' – the things that she has been through in the past. Ask me to describe Evie and I would complicate things. I'd use the language that I have learnt in my professional life in social care. As Evie is also a participant in my study, there can be no doubt that this will influence the ways and means with which I interpret what she says to me and how I represent this to other people.

Fieldnote – 31/04/07

I know Evie has a learning disability. Psychologists have measured and categorized it. But when it comes to certain things – things that seem to really matter the most to Evie – she can be very clever indeed. She can run rings around even the most seasoned professionals when the mood takes her, including me.

On several occasions, Evie has been described to me as 'attention-seeking'. I would add that she is very good at it. She certainly does know how to get our attention. Unlike most other young people however, Evie has her own team of experts; professionals who are watching and analysing her behaviour and her mood, deciding what it all means. She is used to it. She now has her own personal researcher. She appears to accept this as perfectly normal.

Evie went missing in April 2007. This was when she started to fade from sight; gradually at first but soon I was aware that she was no longer where I wanted to her to be - at the centre of the process, at the heart of what I was doing. I started to search for her. Where had she gone? Where should I begin to look for her? She had disappeared into the process, vanished from sight by way of the methodology. I was determined to try to locate her. I missed her. I wanted her back.

Locating Evie

April 2007 was when I started interviewing the six young women who were participants in my doctoral research. They were young women I knew particularly well. I had worked with each of them closely over a number of years as a carer and the house manager in a residential unit at a centre for children and young people with epilepsy. We were not approaching the research process as strangers to one another but as people with established relationships and histories. What I soon discovered however was that in the process of transcribing the interviews something went missing. The warmth and humour that was evident to me when I conducted the interviews was not communicated by a bracketed note - (laughs) – and I started to lament for what was lost in the process.

Transcribed and translated onto the page, the warm, funny and playful communication was not as I remembered it. It fell flat. I could adorn the transcripts with notes in parentheses but felt the need to say and do something differently to communicate more about the situation and the relationships I had with my research participants. I wanted to retain something I felt was special and important. It seemed that there was so much that was lost when the Dictaphone was switched off and the interviews were translated onto the page.

In order to address these misgivings, I started to look to other ways of writing and thinking about representations of research. I wanted to craft something different from the accounts of research I was reading that so often seemed to involve bland and uninspiring reporting of potentially interesting phenomenon. Ethnographic fiction provided the means to address the reservations I had concerning what was being lost in the process. It was this approach which led to the creation of a fictional character – Evie - to express the themes and observations which grew from the research. This allowed me to bring elements of all of the young women in my study into the reporting of the research in a particular way, representing themes in a personal story of the kind I connect to as a reader and which I hope my readers will engage with similarly.

The character of Evie is used in this thesis as an expression of what I have learned and what I felt the need to say about the young women I have worked with, interviewed, written about and thought about and tried to represent in this study. As outlined later in a description of the methodology employed in this thesis, ethnographic fiction has been used in part to report the findings and it accompanies a more traditional analysis of the data taken from a phenomenological interpretation. The intention behind this approach is that each will support a more insightful reading of the other. It is hoped that the juxtaposition will lend itself to a more in depth understanding and appreciation of the research situation and the phenomenon at the heart of this research – the perceptions and opinions of young women with epilepsy as they make the transition to adulthood.

Whakapapa/Identity Statement

In the place I am from it is customary to begin speeches – this being an oral tradition – with a recitation of your '*whakapapa*'. This is an 'identity statement' which is partly genealogical in nature but which will also make reference to the significant places such as mountains and rivers which the speaker has a personal and spiritual connection to before giving a detailed account of tribal affiliations and esteemed ancestors (Barlow, 1991). It is a description of who the speaker is and will inform the understanding that a listener may take from what they have to say.

My origins within a small, predominately Maori community in northern New Zealand have in part shaped my cultural outlook and have therefore informed the way I approach the research process. It is one element of my researcher identity and I am 'situated' by this and other biographical details that will influence how I conduct, interpret and represent my research (Dunne et al. 2005). In order to provide the reader of this thesis with clear orientation, it is necessary to outline a kind of academic and intellectual '*whakapapa*' that describes my 'identity statement' as a researcher. It concerns finding a 'place to stand' in relation to the research (Dunne et al. 2005).

The 'esteemed ancestors' who need to be acknowledged include Edmund Husserl, Martin Heidegger, Maurice Merleau-Ponty and Jean-Paul Sartre. Of particular

importance and significance in relation to this thesis is the work of French sociologist Pierre Bourdieu. I have employed a phenomenological methodology which originates in the work of the German philosopher Husserl and travels to its modern guise through the continuation of this work by his student Heidegger with later contributions from Merleau-Ponty and Sartre (Eatough & Smith, 2008). The manifestation in which this tradition finds its way into this thesis is through the work of Jonathan Smith, Paul Flowers and Michael Larkin, who have developed a relatively new methodological approach that they have termed 'Interpretative Phenomenological Analysis' (IPA) (Smith et al., 2009).

As further explored in the methodology chapter that follows, phenomenology has provided the philosophical underpinning of this research while IPA has been used as a means to translate this foundation into a process. This approach is suited to the motivations behind this research as it places emphasis on the 'lived experience' of the participants in my study and aims to explore their perceptions. As noted within the literature review in this thesis, qualitative research with people with epilepsy is relatively and notably scarce (Andermann, 2000). One of my primary motivations for conducting this study has been to address this situation and to facilitate the inclusion of the voices of young people with epilepsy within the literature. It carries political ambitions in advocating for the inclusion of the voices of people with disabilities in the research literature and also aims to provide insight that could shape professional practice in relation to young people like those who took part in my study.

Part of my identity as a researcher has been influenced through the use I have made in this thesis of Bourdieu's work. His key concepts of field, habitus and species of capital have been used to interrogate the data following the phenomenological analysis. What Bourdieu's concepts offered me as a researcher was a way to connect the relationships between themes that were produced during the analysis and in doing so allowed for the development of a conceptual model which links together different elements concerning how my participants appear to perceive adulthood.

I have come to the social sciences from the arts - as a creative writer - and I am drawing on both traditions throughout this thesis. Within the opening of this thesis there is a conscious attempt to maintain a level of tension; employing a literary device seldom

seen in traditional academic writing, where students are taught to go 'subzero on the tension scale' (Wolff, 2007). The purpose is to capture the reader's attention because, as suggested by Richardson (2003), writers want readers to continue turning pages. It is also hoped that the approach taken lends itself to satisfying one of Richardson's criteria for establishing quality in qualitative research in that it has aesthetic and artistic merit and that it is 'not boring' (Richardson, 2003).

It is however my intention to maintain a high level of openness concerning how this research was conducted and the influences that have been brought to bear on the interpretations in order to avoid the situation as described by Wolcott (2002) wherein – 'Too often, the topics are addressed in elaborate detail before the reader catches more than a glimpse of what the researcher is up to' (Wolcott, 2002, p. 94). I have used ethnographic fiction to draw back the curtain and reveal the dilemmas and difficulties of working and researching with the young women who were participants in my study.

Mona Livholts (2012) suggests that - 'In a time of growing demand for methodological renewal that promotes justice and equality, it brings into question how writing styles have a central place for shaping critical and intellectual work' (Livholts, 2012, p. 14). She refers to the '... transformative dimensions of writing research' and indicates an interest in '... promoting an ethics of change and a renewal of reflexivity' (Livholts, 2012, p.18). The reflexive stance is one which resonates with the use of Bourdieu's work as a theoretical framework as he placed particular emphasis on the need for researchers to reflect on their practice (Bourdieu & Wacquant, 1992).

Related to this reflexive stance is a thread which runs throughout this thesis and which has informed the development of the research and the way in which it has been reported. This is Richardson's concept of writing as a 'method of inquiry' (Richardson, 2003). Writing is a 'way of knowing' (Wolcott, 2001) and it was through writing about Evie and my experiences as a researcher as well as a social care professional – intertwined parts of my researcher identity – that I started to make sense of how I could begin to capture the situation for the page. This has involved adopting a stance as a

'vulnerable observer' (Behar, 1993). The anthropologist Ruth Behar challenges the situation in which, as researchers -

'We ask for revelations from others, but reveal little or nothing of ourselves; we make others vulnerable, but we ourselves remain invulnerable' (Behar, 1993, p. 273).

In addressing the way in which anthropology has been conducted in the past, Behar goes on to state that –

'Our informants are then left carrying the burden of representations as we hide behind the cloak of alleged neutrality' (Behar, 1993, p. 169).

The stance taken in this thesis is one which draws on feminist theory and aims to address in part the - '... question of knowledges. Whose knowledges? Where and how obtained and by whom, from whom, and for what purposes?' (Olesen, 2003, p. 336). This concern with constructing ways of knowing is a theme which runs through this thesis as it aims to challenge the notion that the only way of 'knowing' about young women with epilepsy is through the quantitative measurement of factors relating to a medical condition.

Perhaps the most significant influence of feminist theory in relation to this research is the way in which the interviews have been conducted. I was introduced to Ann Oakley's work early in the doctoral programme at the University of Sussex. She has argued against what she presents as a 'textbook' way of conducting interviews in research. This appeared to involve maintaining distance as an interviewer, limiting the development of rapport and never 'giving the game' away concerning personal feelings (Oakley, 2003). She aimed to challenge the myth of 'hygienic' research and suggested that '...personal involvement is more than dangerous bias – it is the condition under which people come to know each other and to admit others into their lives' (Oakley, 2003, p. 58). This was sound advice to read at the beginning stages of the research process. Rather than viewing the self as a 'potential contaminant' (Fine et al. 2003) during the interview process, the approach taken in this research has involved an open acknowledgement of

the role that my practice experience and other elements of my researcher identity have played in shaping the work and how I have come to interpret my findings.

Design of the Thesis

This thesis has been structured using seven chapters as follows –

Chapter One – Introduction – In the Absence of Loss

The initial chapter in this thesis opens with an observation concerning a puzzle and briefly maintains an enigma for the reader. My intentions in terms of reporting the research in a creative and perhaps unconventional way have been signaled by the use of a literary device. The second part of this introductory chapter refers to the influences that have been brought to bear on the development of this research as a 'Whakapapa/Identity Statement'. Following on from a description of the design of the thesis, this introductory chapter then gives an account of the research questions and the context for the study as well as a brief introduction to the biographical details of the participants who took part in this research.

The final two parts of this opening chapter provide an explanation of the title this thesis has been given and a reflection that came early in the research process and which has in many respects helped to shape my approach and understanding. People with epilepsy may have significant memory impairment (Zemen et al. 2012). When one of the participants in my study told me she had few memories of her childhood as a result of her seizures I felt a sense of loss on her behalf. It soon became clear however that she did not share this feeling and I have introduced the concept of this 'absence of loss' as one of the final points in the introductory chapter in order to signal the need to remain reflexive - aware of my own reactions and sensitive to the perceptions of my participants.

Chapter Two – Methodology & Ethics – Differently

In order to make my means and methods clear to the reader I have initially included a table within my chapter on methodology and ethics that outlines the different methodological elements of the research and how they are related. Prior to conducting this study, I completed a 'Critical and Analytical Study' (CAS) as preparation for the research described in this thesis. The CAS and its relationship to the thesis are initially addressed within the chapter on methodology and ethics. The CAS provided a means to explore the methodological concerns that would shape the eventual thesis and the platform that it provided is outlined as well as a reflection on the departures I have taken since it was written in terms of my methodological approach. Although originally drawn to Life History and Life Story approaches, I subsequently made the decision to use IPA as a methodological approach and the rationale for this is outlined in this chapter.

Reflecting the close connection between decisions relating to methodology and ethical considerations this chapter has been written to encompass both. Denzin and Lincoln (2003a) have suggested that ethical considerations cannot be divorced from methodological concerns. This point could perhaps be taken further with the suggestion that there are no research concerns that can be detached from ethical considerations. I have outlined ethical dimensions of the research in this chapter before further detailing the methodological approach. I have also drawn on my recent experience of undergoing ethical review for research through the National Health Service (NHS) National Research Ethics Service (NRES) to illustrate current controversies in relation to ethical regulation.

The 'philosophical home' of this work is situated within a phenomenological framework through the use of IPA. The philosophical background to this approach is outlined within the chapter in this thesis concerning methodology. In particular I have outlined the primary influences on IPA – phenomenology, hermeneutics and idiography (Smith et al. 2009). The decision to use ethnographic fiction to situate and expand on the findings is explored in the chapter on methodology as well as links to earlier ethnographic work. This chapter also introduces the rationale behind my decision to use Bourdieu's concepts to provide a theoretical framework as a means to interrogate the findings. The

use of writing as a 'means of inquiry' has been further elaborated on in this chapter. I have also detailed how the methodological literature was identified. The final part of this chapter outlines how the literature search was carried out and an argument is made for developing a 'bespoke' literature review that fits with the other elements of this thesis rather than providing the reader with an 'annotated bibliography' of the reading I have undertaken.

Chapter Three – The Literature Review – Expectations of Ordinary

As noted in the introduction to my literature review, my participants revealed what I have termed 'expectations of ordinary'. They expected to get jobs, pay bills and have families and the barriers – epilepsy, learning disabilities - that could make these aspirations more difficult for them to achieve than they would perhaps be for their non-disabled peers are conspicuously absent as factors for consideration. I have used this observation as a starting point for a review of the literature as it illustrates how the process of reflecting on my practice experience as well what I was learning through the research process maintained what I have termed 'background noise' when I came to reading and reviewing the literature, informing my interpretations. I was also challenged to consider my practice in light of my reading.

In order to provide the reader with orientation and context I have briefly outlined what epilepsy is and the impact of the disorder in terms of potential for comorbid conditions and psychosocial impact. I have gone on to explore the characteristics of current epilepsy research and made an argument for other ways of looking at the experiences of young people with epilepsy. Following on from this, I have drawn on qualitative research involving young people with epilepsy. The next part of my review concerns the transition to adulthood for young people with learning disabilities and I have used this section to 'look forward' to the findings and considered three of the themes that developed in relation to the literature. The final part of my review concerns theories on the transition to adulthood and how they relate to the findings from this research.

Chapter Four – Findings Part I – Alcohol, Adulthood & a Certain Way of Being

There were five primary themes that emerged from the phenomenological analysis of the data and these have been outlined within the first of two chapters in this thesis that report on the findings. It would seem that the participants in my study had particular and rather prescriptive ideas concerning how the transition to adulthood was 'achieved' and how they would gain adult status through certain behaviours. I have described them collectively as a 'code of behaviour'. These themes have been explored in turn and illustrated using quotations from the interviews as a means of opening the data to the reader. These themes form the basis for the conceptual model as outlined in the discussion chapter. I have also included discussion of the 'perceptions of epilepsy' revealed by my participants in this chapter of the thesis. Although this was not the focus of the research this topic was addressed in the interviews and what was revealed by my participants was a highly variable response to the experience of having epilepsy.

The sociologist Gerhard Nijhof, in his study of the lives of twenty people with epilepsy, referred to the heterogeneous nature of the experience of having epilepsy as described by his participants that was at odds with the way in which previous research had presented an homogenous account of what it means to have the condition (Nijhof, 1998). He attributes this to the mindset of researchers who worked from interpretations that were preset and failure to use a 'grounded theory' approach that could open up a range of interpretations. The methodology employed in my own research likewise seemed to lend itself to revealing perceptions that were more heterogeneous than other kinds of research might have done.

I have discussed perceptions of epilepsy as a means to further the argument for more research with this population that includes their perspective. Commenting on 'disabled family life', Dan Goodley suggests that - 'Much previous British research on disability and its effects on family life has seen the impairment as a personal or family tragedy' (Goodley, 2006, p. 630). Likewise the weight of research into the associated difficulties that can come with a diagnosis of epilepsy would suggest that the experience of having the condition is a kind of personal as well as family tragedy. This did not appear to be the perception of my participants and responses varied when I asked them about what it

meant to be a young person with epilepsy. Life with epilepsy was presented as sometimes difficult but by no means tragic.

Chapter Five – Findings Part II – Evie/I

The second chapter which reports on the findings of the research is written as ethnographic fiction. It tells the story of Evie, a character who has been introduced in the opening notes in this thesis. Her narrative is in part my own as a practitioner-researcher and it draws on professional experiences and personal observations. It includes description of the many influences and factors which have been brought into play in the research process. It is told in three parts, detailing the day-to-day relationships I have with my students as carer, the one which developed as a researcher and one which touches on the influence of my knowledge of past histories. The intention behind providing the reader with the juxtaposition of these two different accounts of the research findings is that they will allow for a better understanding of the themes that developed and an appreciation of the context and setting for the research. Within one life, there are many lives. I brought several different kinds of identity to the research process - as a professional carer, researcher, writer, all elements of habitus, all influential and I was accountable in different ways and had different motivations as a result of each of these identities.

Behar (1993) addresses this issue of motivations and different kinds of ‘selves’ –

‘As I wrote, the ethnographer in me wanted to know: Who is this woman who is writing about others, making others vulnerable? What does she want from others? What do the others want from her? The feminist in me wanted to know: What kind of fulfillment does she get – or not get – from the power she has? The novelist in me wanted to know: What, as she blithely goes about the privilege of doing research, is the story she isn’t willing to tell?’ (Behar, 1996, p. 20)

Behar (1993) argues for the importance of revealing ‘the self who observes’. She makes a compelling case and the ethnographic fiction included in this thesis is in part autobiographical and aims to reveal ‘the self who observes’. Attention is also drawn

throughout the ethnographic fiction to the deliberate act of interpretation, to the way in which a writer – of any kind - may embellish for their own purposes.

Chapter Six – Discussion – Bourdieu & the Capital of Adulthood

Chapter six of this thesis is a synthesis of the findings from the two previous chapters and it uses Bourdieu's concepts of species of capital, field theory and habitus as a theoretical framework to achieve this. It also introduces the conceptual model that has been developed through consideration of how the themes developed from the phenomenological analysis are related to each other concerning how my participants perceive adulthood and the ways in which adult status can be achieved. This conceptual model outlines what I have termed the 'capital of adulthood'. I have also considered how my own experience of the transition to adulthood has shaped the interpretations I have developed from analysis of the data and the understanding I bring to the research situation. My own habitus will have a bearing on how I have interpreted all of the elements of the research and this has been addressed briefly in the ethnographic fiction and outlined more fully in the concluding part of the discussion chapter that uses Bourdieu's work as a theoretical framework.

Chapter Seven – Conclusion – Evie in the End

The concluding chapter of this thesis opens with contemplations concerning what I have learned about Evie – and by implication about young women who share her characteristics – through the research process. I have summarized the research and outlined the contribution it makes to our understanding of the lives of young women with epilepsy and learning disabilities. Within this chapter I have used Lucy Yardley's (2008) criteria for quality in qualitative research to assess the research and I have also drawn on Richardson's (2003) criteria for how she feels qualitative research should be judged. I have detailed the ways in which I hope to disseminate the research. The scope for further work is discussed in the final parts of the concluding chapter, with particular

consideration for the kind of research that could grow from this present study. This thesis concludes with a return to the sense of obligation that began the process, sustained it and remains in place concerning the need to create more research of the type that includes the voices of young people with epilepsy.

Research Questions

It took three years to write a question. This was an observation shared with me by a fellow doctoral candidate and it was also true for me that considerable time passed between the initial thought that I should begin conducting social science research with the young people I worked with and the final formulation of the research questions. Although I knew that I wanted to conduct research that would include young people with epilepsy as ‘participants’ and not ‘patients’ it was the choice of IPA as a methodological approach that narrowed the concerns of the research sufficiently to allow for the formulation of research questions.

IPA is a methodology that focuses on a particular phenomenon that the participants in the research have in common and this methodological approach aims to explore the meaning they take from their experiences and their perceptions of the phenomenon (Smith et al. 2009). The ‘common phenomenon’ that seemed to hold the most significance and interest for my participants was the transition to adulthood. While I was interested in life within the ‘medical model’, this was a situation my participants had lived with most of their lives and it seemed to be unremarkable to them and not a topic they would want to spend time discussing. Deciding that it would be appropriate to situate the research in an area that was a central concern for my participants led me to the transition to adulthood. The research has focused on the following questions -

- What does it mean to be an adult for the young women in my study?
- What makes a person an adult according to my participants?
- How have the circumstances of the lives of the six young women in my study shaped their understanding and perceptions of adulthood?

As noted by John Creswell - ‘... our questions change during the process of research to reflect an increased understanding of the problem’ (Creswell, 2007, p.43). He states that ‘... a researcher begins a qualitative study with general questions and refines them as a study proceeds (Creswell, 2007, p. 78). This opinion is supported by Jane Agee (2009) who suggests that - ‘... changes in questions should also emerge from the researcher’s capacities to examine their own roles and perspectives in the inquiry process, especially how they are positioned in relation to the participants’ (Agee, 2009, p. 431). This was certainly true in my experience and how I positioned myself initially in terms of directing the types of questions that would be addressed in the research changed as a result of engaging with the interests and experiences of my participants.

Research Participants

Table 1.1

Participant	Age at time of research involvement	Diagnosis
‘M’	22	Epilepsy, learning disability
‘A’	22	Temporal lobe epilepsy, learning disability, hearing difficulties
‘L’	20	Epilepsy, learning disability, emotional problems
‘C’	21	Epilepsy – Lennox Gastaut Syndrome, learning disability
‘J’	21	Epilepsy, behavioural problems, learning disability
‘G’	22	Epilepsy, history of behavioural problems, social and memory difficulties with low self-esteem, learning disability

I first met the young women who were participants in my study when they were in their mid to late teens. For the most part I lost contact with them when they moved away at the end of their time at the epilepsy centre where they lived for 39 weeks of the year as part of their educational placement. I spent a great number of hours in the company of these young women and I knew them well. One of the challenges in this thesis is to be sufficiently descriptive of a situation I am very familiar with in order to provide insight for the reader, making no assumptions concerning prior knowledge of the kind of world in which the research was conducted. I have written short descriptions as a means to introduce the participants to the reader in more detail than a table would allow. I have chosen to write about the research using a particular story through the use of a fictional character who takes elements from each of the participants but it needs to be acknowledged that behind the fictitious character are six very real young women.

Four of the participants in this study are White British while 'A' is British of West African heritage. 'G' has mixed Welsh and Italian heritage that she identifies with strongly. All of their parents were in full-time paid employment at the time that the participants took part in my study. Three came from homes where both parents were still married to each other while 'G' has parents who have both remarried. 'A' had been raised by her mother but had regular contact with her father. 'J' had been raised by her mother but was in the care of her father at the time of the study following her mother's death. While it has not been possible in the context of this study to explore in more depth how their cultural and family backgrounds have influenced the perceptions of my participants as individuals it is important to acknowledge that they came from a range of situations. What they had in common was epilepsy, a learning disability and placement in my care at the epilepsy centre where this research was conducted. While I have aimed to explore their common ideas and experiences it must not be overlooked that they were also individuals.

Referring to her longitudinal study exploring gender and change in the lives of young people, Rachel Thomson (2011) suggests that –

'Each of the young lives that make up the Invented Adulthood study is unique, yet they are patterned in systematic ways by location, common values, comparable resources and shared experience' (Thomson, 2011, p. 11).

Likewise I have needed to present what I found to be common experiences and attitudes within this group of young people while recognizing their individuality. Within this introductory chapter, I also want to make a brief mention of the relationship that I had with each of the participants as a practitioner-researcher. Some of the participants in this study were interviewed only once and some were interviewed on more than one occasion. Although all of the participants were keen to be involved in the research I needed to take into consideration their social lives and the amount of time it was reasonable to ask them to give to the research.

'M' is diagnosed with epilepsy and a learning disability. She also has Non-Epileptic Attack Disorder (NEAD), a condition which is psychological in origin wherein a person will present with seizure symptoms but the cause is not neurological. We called these her 'emotional seizures'. In common with all of the participants in this study, 'M' has a learning disability in addition to her diagnosis with epilepsy. She attended a mainstream primary school where she says she was bullied. She went to a special school for her secondary schooling and reported that this was better for her and she was happier there. Of all of the participants in the study, I knew 'M' for the longest period of time. She was very motivated to be in the study and two further interviews took place even after she had left my care. I completed five interviews in total with 'M', ranging in length from 30 minutes to more than an hour.

'J' was diagnosed with epilepsy as a small child and she reported that it was her grandmother who initially noticed she was staring and her eyes were rolling backwards into her head. She recalled mixed experiences in her education. She said that her learning disability 'bothered her' more than her epilepsy because there is the chance that the epilepsy might go away and the learning disability is permanent. Her mother died shortly before 'J' came to be in my care and we had talked at length and covered emotional territory prior to her involvement in the research. We had done a lot of talking before we began the interviews. I interviewed 'J' once for 45 minutes. It is my impression that the amount of talking we had done prior to the interview was actually a barrier as 'J' did not seem to feel the need to elaborate on topics that she had already

discussed with me in the past. The interview did however provide me with some useful observations that helped to inform the process at the stage of analysis.

'L' was also diagnosed with epilepsy as a child and she has emotional and behavioral difficulties that she reported were difficult for her family to cope with. 'L' was close to her family but I knew from conversations with her mother that they had struggled and the residential placement was helpful for 'L' to build positive relationships with her family. The interviews I did with 'L' were fluent and reflected an existing rapport that seemed to help facilitate the interview process. I interviewed 'L' three times ranging in length from 30 minutes to 50 minutes.

'A' recalled during the interview we did together that she used to be bright and was able to read passages from the bible as a small child. The epilepsy has – according to her account - 'slowed her down' however and she was not able to cope with mainstream college. She was the most talkative of all of the participants in my study and she seemed to particularly enjoy the opportunity to be involved in the study. I interviewed 'A' once for one hour and twenty minutes. Although I would have liked to have carried out more interviews with 'A' the sociable nature that made her willing and able to engage with the interview process also meant that she had a particularly active social life and this took up a lot of her time. She had little time for involvement in my research despite her willingness.

'G' had surgical treatment for her epilepsy while she was in my care, two years before she was involved in my study. This meant that she no longer had seizures and she felt that she had 'moved on'. However, 'G' still has a learning disability and although I felt that this would continue to impact on her life and the opportunities she would have 'G' expressed ambitious career plans during the interviews I did with her. I interviewed 'G' three times, the interviews ranging in length from 45 minutes to one hour.

'C' has Lennox Gaustaut Syndrome, an epilepsy syndrome that is associated with multiple seizure types, frequent seizures and developmental delay. 'C' appeared to have 'less talk' in her than some of the other participants and despite a positive relationship in the care environment I struggled to maintain fluency in the interview I did

with her. However, when analyzing the data I realized that what she had said did provide me with insight and – as it was with all of my participants – what she did not say was equally as interesting. I interviewed ‘C’ once for 45 minutes.

The participants in my study were approached because I felt they would enjoy the process of being interviewed. One potential participant declined involvement, which suggested I was successfully conveying the voluntary nature of taking part in the research. Sample size is important when using IPA as a methodology due to its concern for the careful analysis of the ‘particular’ and it has been suggested that – ‘... it is more problematic to try to meet IPA’s commitments with a sample which is ‘too large’, than with one that is ‘too small’ (Smith et al. 2009, p. 51). I made the decision that six was a sample size that would allow me to explore the experiences of my participants in sufficient depth while including a possible range of responses to the research questions.

The decision to exclusively interview young women was naturally not inconsequential and as later outlined, having epilepsy as a woman is not the same as having epilepsy as a man due to gender-specific issues relating to reproductive health (Morrell, 1999). Although I had not initially set out to focus on the experiences of young women, by the time I was starting to conduct the research I was working exclusively with young women. I could have approached young men I had worked with previously to take part in the research but I felt that the positive ‘here and now’ relationship I had as carer for my participants at the time of their involvement in the study was important and I wanted to use the rapport we had to facilitate the research.

Research Setting

In order to provide my reader with orientation concerning the setting for this research it is necessary to give a brief overview of the nature of the situation in which it was conducted. My role as ‘house manager’ of the residential unit where the research was carried out was to oversee the small team that I conceptualise as a ‘professional family’. We were the people who were charged with ensuring the well-being of the young

women in our care. We were also responsible for helping our students to develop the practical and social skills that they would need to gain further independence.

At the centre of my relationship with my participants and the other young people I cared for was a domestic routine. We ate our meals together and talked at length at the kitchen table. We shared jokes and stories. I taught my students to cook using recipes taught to me by my mother. At the periphery of the 'home life' of the unit, I was also completing risk assessments and documenting seizures, recording information, arranging staff training and supervision and carrying out a vast number of administrative tasks. I asked my students one day – 'What am I doing when I am doing work?' and the consensus was clear. Paperwork. This was what I did when I did 'work'. It would seem that everything else I did while I was on the residential unit was just 'living'. This impression was reiterated in the interview I did with one of the participants in this study when I asked her about living with staff in the place of family members. This was 'normal' in her opinion and 'C' concluded it was – 'Just like living with a family'.

The work that staff undertake on a care unit can be difficult to define. It is my feeling that it is more than the sum of administrative and routine tasks and I would place close engagement with the young people we were supporting at the heart of the work that we were doing in the residential unit. Those who have little understanding of residential care in this type of setting may not understand what care workers actually do on a day to day basis. The answer is that they are juggling the demands that come with any domestic life as well as providing routine care – administering medication, managing seizures – and doing so while coping with the other competing demands that come from working with a group of young people with varied and complex emotional needs.

I have provided this 'snapshot' of life and work on a residential unit in order to provide context for the research. This is where Evie's story takes place and where the story of the research is centred. It is also my 'professional home' and the use of ethnographic fiction within this thesis has provided a way to capture and include the practice experience that had shaped and informed my approach to the research.

In a comment that particularly resonates with my own motivations for using ethnographic fiction Kay Inckle (2010) refers to her experiences in a similar setting –

'In my previous role as a residential support worker, in some of my early, but not fully endorsed research conversations, in many discussions within my personal sphere, I had amassed a whole reservoir of highly formative knowledge which I desperately did not want to have to entirely abandon and yet nor could I make direct reference to. Moreover, much of this 'lived experience' was so integral to the development of my research that it seemed both impossible and unrepresentative to attempt to exclude it altogether from the trajectory of my work' (Inckle, 2010, p. 32).

It must be noted that the setting for this research was not a generic residential care unit. It was within an epilepsy centre that has been in existence for over a hundred years. It is one of several such centres in Europe. The history of centres of this type is outlined by Albert Aldenkamp (2010) who details how –

'Epilepsy centres started their lives as 'colonies', large facilities, often outside the community in rural areas. Most of the epilepsy centres were founded in the late 19th century, often started by a few people and driven by Christian ideals of providing care and offering dignity... Like the asylums of the late Victorian era, the epilepsy colonies served as isolated communities where the afflicted were protected from stigmatizing public view' (Aldenkamp, 2010, p. 625).

Aldenkamp (2010) goes on to state that these former epilepsy 'colonies' now exist in a different incarnation and many are 'centres of excellence' which offer specialist treatment and care. The centre where this research was conducted began to specialize in the care of children and young people with epilepsy shortly after the Second World War and has gone on during the following decades to develop educational as well as medical services within the campus.

Those who now work within the epilepsy centre where this research was conducted are perhaps differently motivated from the Christian brothers who founded the centre as a kind of asylum to hide people with epilepsy from public view. Aldenkamp (2010) has entitled his history of epilepsy centres in Europe 'From Colony to Community' and has emphasized the move away from the model of the asylum to the development of

communities where specialist care and treatment are offered. While it is perhaps not necessary to give a more detailed history of the centre where this research was conducted it is important to provide some insight into the kind of community where the participants in this study were living. The residential unit that was the setting for this research was a part of a wider field within the community of the epilepsy centre and, as later outlined in this thesis, both could be seen as influential in the development of the views and perceptions, innate beliefs and 'habitus' of the participants in this research.

Whether or not I should specifically name the epilepsy centre where this research was conducted was a point that was discussed with my supervisors in the final months before the submission of this thesis. Although permission had been granted to carry out the research at the centre, the 'gatekeepers' who had made this decision had since moved on and had been replaced by others. Following further consideration I decided against specifically naming the centre within this thesis. Professionals and others connected with the 'world of paediatric epilepsy' would have no problem guessing where the research was set. Those with no such connection would not gain a better understanding of the research had I named the centre and although I would suggest that the risk of damage to the centre's reputation from this research is low there was no benefit that could justify this risk. I have therefore referred to the setting for this research generically as a 'residential unit' within an 'epilepsy centre'.

Learning & Loss

I learned very early in the research process to question my own responses in relation to what I was hearing from my participants. One revealed that she knew very little about her childhood, only what she had been told it seemed –

Interviewer – what were you like as a child?

'L' – I've been told I was a quiet child. Didn't communicate much. Didn't hardly talk at all. Shy. Quiet.

'L' explained that she knew so little about her childhood as a result of memory problems related to her epilepsy, which had been uncontrolled. It was not until she came to the assessment service at the epilepsy centre aged fourteen that more effective drug therapy was introduced. This was when she began to keep hold of her memories –

'L' – That was when they sorted my drugs out. I started to remember more and I could start to learn properly. Before that – (laughs) - there wasn't much.

I found this account very sad initially. It was as if 'L' was telling me that she did not have a childhood, which seemed to me to be an injustice brought about as a result of inappropriate treatment for her epilepsy. I felt a sense of being aggrieved on her behalf. However, she stated that –

'L' – That's how it was. I don't... I don't feel anything much about it. One way or the other.

I remember noticing her attitude, her slight shrug; the factual tone. She was not telling me these things to evoke an emotional reaction. She did not seem to consider this situation to be sad, or even particularly noteworthy. In her view it seemed that it was a fact. I realized that I would need to keep this 'absence of loss' in mind as I conducted my research and analysed the emerging themes. I would need to listen closely to what my participants were telling me and the way they were saying it. I would need to pay attention and keep hold of the focus on their perceptions.

A Place for Talking

The title for this thesis comes from a child's drawing of the campus at the epilepsy centre where the research described in this thesis was conducted. It was drawn in 1931. The artist was a young girl by the name of Lila Fox. She was the medical superintendent's daughter. It notes the various features of the setting – playing fields, the children's homes, local cottages and farm buildings. It includes notes, details of the different activities that took place in particular parts of the site. There have been some significant changes since this time. The sanatorium depicted in the drawing is now a

£7,000,000 'state of the art' medical centre. The farm has been scaled down and self-sustaining horticulture has long since ceased.

Still there, at the centre of the campus, however, is a duck pond. It is the view from the residential unit I was managing when conducting this research and the setting for most of the interviews that took place. The bend in the lane, next to the duck pond is, according to the young artist's drawing, 'a place for talking.' It is at the centre of the campus, close to the dining hall and where people pass each other on the way to other places and I have noticed they often stop to talk. I like the community aspect of daily life within the campus. I wanted to reflect this in the study I conducted. I wanted the research to be a place for talking.

Chapter Two – Methodology & Ethics - Differently

Origins & Influences

The genesis of the research described in this thesis rests with a desire to do research ‘differently’ with young people with epilepsy. I was motivated by the need to ensure that they are represented in the literature in a way that includes their voices and focuses on their ‘lived experience’ rather than their medical condition. This chapter of the thesis aims to clarify how I developed my methodological approach from its beginning point as an aspiration to do research differently with the young people I was working with to its conclusion as the basis on which the research was conducted.

There are a number of significant theoretical influences that have shaped the methodological approach taken in this research and they need to be acknowledged and elaborated on in terms of the rationale for their use and the ways in which they have shaped the research and how it has been represented in this thesis. These include Bourdieu’s key concepts and phenomenology. As noted, IPA has been adopted as one part of the methodological means used to explore the experiences of the young women in my study. The origins of this approach are detailed within this chapter. I have also outlined the history of ethnography as a discipline and the use of ‘new ethnography’ as a strategic approach that encompasses ethnographic fiction (Lincoln & Denzin, 2003b). This is followed by consideration of ‘writing as a method of inquiry’ and the way in which the methodological literature was explored. The final part of this chapter of the thesis is an account of the literature search and review and an argument concerning the need to create a review that would fit with other elements of this work.

In order to provide a clear indication of how theoretical influences have guided the methodological approach taken in this research and how they have been translated into research methods and the reporting of the research I have outlined the different elements of the process in the table below -

Table 1.2

Epistemology	Theoretical Perspectives	Methodology	Methods	Reporting
Constructionism	Phenomenology Bourdieu's key Concepts Feminist Theory	IPA	Semistructured Interviews Observation Reflexivity Writing as a method of inquiry	Phenomenological analysis synthesised with Bourdieu's key concepts Ethnographic fiction

Adapted from Crotty, 2003, p. 5

It has been suggested that ethical considerations should be more than a 'tick box' exercise to be completed in order to satisfy institutional requirements but must be used in order to guide the conduct of the research throughout every stage of the process (Iphofen, 2011). Within this section of the thesis detailing ethical concerns I have also outlined controversies relating to how research is regulated and illustrated this from my recent experience of gaining ethical approval - for a study I conducted subsequent to my doctoral research - through the National Health Service (NHS) National Research Ethics Service (NRES).

The processes for gaining ethical approval from the University of Sussex and gaining informed consent from my participants are also outlined. I have then detailed how the data were produced and analysed. The initial part of this chapter is an overview of the Critical and Analytical Study (CAS) that was conducted in preparation for the research described in this thesis.

Critical and Analytical Study

It struck me – I wrote – as both curious and sad. This observation was the opening for the CAS that I completed the year prior to beginning my doctoral research. What I was referring to in my opening line of the CAS related to the medical descriptions I had read concerning the young people I was working with when I entered the field of social care and started as a support worker at the epilepsy centre where this research was conducted. I made particular reference in the opening to the CAS to notes I had read about a young man who was described in a medical report according to certain physical characteristics. It was recorded that he had ‘diamond-shaped eyes’, a ‘pigeon-shaped chest’ and ‘rocker-bottom feet’. I understood the reason why these notes would have been made – as unusual physical characteristics might have hinted at a genetic cause for this young man’s learning disability – but I found the way in which a person had been reduced to this record of ‘bodily abnormalities’ to be dehumanising. The CAS was used to state my intention to conduct research that would include the ‘whole person’.

Ken Plummer (2001) has suggested that –

‘Most social science is involved in a process of amputation. Psychologists will amputate a ‘personality’, the ‘attitude’, the ‘intelligence quotient’ from the totality of the life experience while sociologists will amputate the ‘structure’ and the ‘culture’ from the totality of daily lived experience’. (Plummer, 2001, p.40).

Plummer contrasts this with a Life Story approach that will consider the ‘totality of the biographical experience’ (Plummer, 2001, p.40). I was drawn to Life Story and Life History methodologies as an approach that would remedy this sense of ‘amputation’ that I felt characterised so much of the medical research into epilepsy. However, what I concluded after further reading and reflecting was that creating this sense of ‘wholeness’ was not unique to these particular qualitative methodologies and could be created using different approaches. As noted, I also needed to consider the time that my participants could give to the process of building a detailed account of their lives. While my participants were all keen and motivated to be involved in the study it must be recognised that they had busy social lives. I needed to be aware of their priorities.

One of the significant factors that influenced this research is that all of the participants in the study have learning disabilities. This means they were not the articulate participants apparently 'prized' by qualitative researchers (Darlington & Scott, 2002). Memory difficulties are common in people with epilepsy (Zemen et al. 2012) and this had a bearing on the ability of my participants to reflect on their experiences. However, as argued through the CAS, it is both possible and also important to conduct research with people with learning disabilities, communication difficulties and memory loss (Booth & Booth, 1996; Goodley, 1996; Rogers, 1999; Walmsley, 2001). I would argue that the relationships I had with my participants was a factor that mitigated against some of the difficulties in conducting research based on interviews with young people with learning disabilities and memory problems. I knew how to talk to these young women and how to get them to talk to me.

As well as providing an opportunity to explore the methodological possibilities and space for reflection on the forthcoming research, the CAS was used as a beginning point for the literature review that has been conducted for this thesis. I looked at current epilepsy research and drew on the narrow range of research that takes a qualitative approach when exploring issues relating to epilepsy. The CAS provided a platform for the research that grew from it and although it was eventually taken in a different direction in terms of the methodology adopted it played an important part in the development of the ideas and ambitions that would shape this research. Writing as a 'method of inquiry' has been integral to the development of this thesis and the CAS provided the space to develop ideas and hone my knowledge of the subject area.

Ethics – Considerations & Concerns

Brinkman & Kvale (2005) draw attention to and question what they term the 'ethicism' that 'permeates the discourse on qualitative research' (Brinkman & Kvale 2005, p. 157). They refer to the position supposedly held by some that qualitative research is ethically 'good in itself', or at least ethically superior to the 'uncaring' quantitative approaches (Brinkman & Kvale, 2005, p. 157). Taking a particular methodological approach does

not of course automatically guarantee the ethical conduct of a study and nor should an alternative approach be read as an indication that the work has been carried out in a less sensitive and ethical manner. There are however differences inherent in asking participants to take part in different kinds of research.

There are also different ethical concerns to be taken into consideration when researching with a population who could be viewed as vulnerable – such as young people with learning disabilities in my case – and when the researcher is clearly in a position of power, also an element of my study. I was the house manager of the residential unit where my participants lived and my actions in all areas of my practice had a considerable influence over their lives. This was the situation that we were in and I certainly did not feel that ethical considerations could be easily surpassed or overcome simply because I was using a qualitative approach in my research. Kvale & Brinkmann (2008) make the point that the ‘... research interview is not a conversation between equal partners because the researcher defines and controls the situation (Kvale & Brinkmann, 2008, p. 3).

Darlington & Scott (2002) raise the issue that the situation is more complex in relation to the kind of research situation I was in. They caution that –

‘A central issue in human services is the complications which arise when the researcher is also the service provider, as the capacity of a client to consent can be diminished by the unequal power and the dependency typically entailed in the worker-client relationship’ (Darlington & Scott 2002 p. 25).

There was no way of changing the relationship I had with my participants. I could not ‘step out’ of my relationship with them in order to conduct the research. What I could do was to acknowledge the nature of the relationship and ensure that as much as possible there was clarity about the voluntary nature of participation and the right of my participants to withdraw at any time. The purpose of outlining the approach taken when considering ethical concerns in relation to this study is to clarify not only the processes which were undertaken to ensure institutional requirements were met but to also detail

the considerations that were a part of an ongoing concern for the ethical conduct of the research.

Guillemin & Heggen (2011) maintain that novice researchers must be trained to be ethical practitioners and that this goes further than learning how to gain approval from an ethics committee or making oneself familiar with a code of practice. They use the term 'situated ethics' to reflect a concern with the development of awareness, judgment and perception that can be called on when in the field in relation to varying factors. Likewise, Shaw (2008) expresses concerns that relying on codes for ethical guidance could compartmentalise ethical considerations into a preamble to research. He looks to the capability of the researcher and the 'moral character of the practitioner' rather than 'technical competence or grand ethical principle' (Shaw, 2008, p. 411).

Halse & Honey (2007) state that the -

'... institutional discourse of ethical research (too) often represents the practice of research as an ordered, linear process with objective principles/rules that inform/direct ethical decision making and moral action' (Halse & Honey, p. 336).

This ordered and linear process is certainly not my personal experience as I wrestled with ethical considerations from the outset. Partly this was as a result of the feeling that I was 'foraging for data' in the personal lives of my participants. Plummer (2001) asks - '... who is this sociologist, psychologist or anthropologist who thinks they have the right to 'seduce' these stories out of people' (Plummer 2001 p. 41). I shared this sense of doubt concerning what right I had to gather the stories of participants in part for my own purposes. I also recognised that they wanted their stories to be told and I felt the need to ensure that other professionals working with young women like my participants had a better understanding of their perceptions and the way in which their experiences shaped their view of the world. I was also aware that if I did not tell their stories it was unlikely that anyone else would. While there were ethical considerations concerning the conduct of the research there were also compelling reasons – from an ethical standpoint – for carrying out the study.

Institutional Consent

Approval was given to begin the research at the epilepsy centre where it was conducted in a meeting of the Health Services Directorate in early 2007 in my absence. I had outlined the research questions and the purpose of the research and it would seem that this was deemed sufficient. It was apparently not thought necessary for me to make an application to the Central Research Ethics Committee (COREC) to carry out the research – as I would have done for more traditional medical research - and I received an email from the Research Coordinator confirming that I was free to start the research. Although there can be no doubt that removing the barrier of a lengthy ethical approval application within a system perhaps more attuned to different kinds of research was helpful in the initial stages of the study it was concerning that a higher level of scrutiny was not thought to be necessary with regard to the work I was undertaking with potentially vulnerable participants. It is worth noting that these procedures have been tightened considerably and now all research at the centre must undergo external ethical review through the National Research Ethics Service (NRES).

The process of gaining ethical approval at the University of Sussex involved completing a checklist was used to ensure that relevant angles relating to the ethical conduct of the research had been taken into consideration (see Appendix 1). There were six standards which concerned safeguarding the rights of those involved, consideration of the impact of the research process on the participants, upholding the highest standards for the research, ensuring external professional ethical approval was granted where relevant, ensuring the safety of researchers undertaking fieldwork and ensuring relevant legislative and policy requirements were met. Guidance concerning the ethical conduct of the research was also given through contact with my supervisors.

I made the decision not to consult the parents of my participants prior to commencing this research, in recognition of the fact that my participants were adults with the ability to consent to their involvement. Under the Mental Capacity Act (2005) it must be assumed that all people have the capacity to make their own decisions unless proven otherwise. Nonetheless, this decision not to consult parents is a departure from ‘standard practice’ at the epilepsy centre where the research was conducted as parents are routinely

consulted on even the most mundane, day to day decisions. However I feel that it is important to provide the young people in my care with as many opportunities as possible to make autonomous decisions as adults and the decision to participate in research is one of them.

Informed Consent/Anonymity

To address the need for informed consent, I developed a participant information sheet which outlined what my students were consenting to and reiterated that I would not be upset with them if they chose not to participate (see Appendix 2). It was presented in language I was confident they could understand if it was explained to them and this information was given in both verbal and written forms. Consent forms were used to confirm willingness to be involved in the study (see Appendix 3). As noted, there was one potential participant who declined involvement in the study and this confirmed for me that I was presenting the information in a way that made it possible for my students to refuse to participate. Within the participant information sheet, I included information regarding familiar people my participants could talk to if something 'sensitive' came up in the interviews. I gave the name of a psychologist and a staff member with Safeguarding responsibilities at the centre in case my participants did not want to discuss something with me that had been raised in the interviews. Prior to each interview I gave a verbal preamble and stated that my participants could withdraw from the study at any time or pass on questions they were not comfortable answering.

All of my students were offered anonymity, initially and in later discussions but they did not express an interest in taking it. I made a decision to use what Darlington & Scott (2002) refer to as 'justified paternalism' and chose not to use my participant's names but to use an initial instead in the reporting of this research. I was aware that although my participants had agreed to be involved in the research, their families and other people they might refer to in the interviews had not. They shared intimate details about their relationships with their parents and siblings in the interviews and this was a further ethical dimension that I felt needed to be taken into consideration.

Controversies in Ethical Procedures

I would liken it to standing trial. I had prepared my 'defense' thoroughly and was supported by my 'legal team' – an experienced Research Coordinator – but I could not help but feel that I was being accused of a crime that I had no intention of committing. This 'crime' was the insensitive and unethical conduct of a small-scale qualitative study. Also on trial – I suspected - was my choice of a qualitative methodology. This is how it felt when I faced an NHS Research Ethics Committee in March 2012 when I was seeking approval to carry out research regarding the educational experiences of children and young people with epilepsy. This was work that I carried out subsequently following the completion of my doctoral research and I have briefly outlined this experience as it illustrates one of the current controversies in ethical approval procedures. This thesis is in part an argument for more qualitative research into the experiences of young people with epilepsy and it is pertinent to note that one of the barriers to ensuring that their voices are heard within the literature – as with other people who could be viewed as vulnerable - may in fact be attempts to protect their interests.

Prior to beginning my research into the educational experiences of children with epilepsy, I was 'called to appear' in an ancient London hospital before a committee of reviewers, mostly from medical professions. Concerns were expressed about the wording of particular items on my participant information sheets. While I tried to keep my information sheets tightly edited and more likely to be read by the participants, the committee members seemed to want to provide more and more elaborate detail, spilling over to four pages. Although provisional consent was given at the initial meeting, revisions and clarifications were requested and reviewed by the chair of the committee and the process from the initial phase and submission of the application form to gaining final written confirmation of approval took seven months.

Hammersley & Traianou (2012), when introducing the topic of ethics in qualitative research, outline the history and development of research ethics by referring to The

Nuremberg Code (1947) and the World Medical Association's Helsinki Declaration (1964) as well as Belmont Report of 1979, which was partly a response to the Tuskegee Syphilis Study in which poor, rural, black men were left untreated for syphilis despite the development of effective treatments due to the scientific interest in understanding the course of the disease. These are important reminders concerning the need for careful ethical regulation of research. To judge all contemporary research against standards that have been developed to protect people from the brutality of the past is perhaps not always helpful however.

Robert Dingwall (2008) argues that -

'The system of pre-emptive ethical regulation developed in the biomedical sciences has become a major threat to research in the humanities and the social sciences (HSS). Although there is growing criticism of its effects, most commentators have tended to accept the principle of regulation. This paper argues that we should not make this concession and that ethical regulation is *fundamentally* wrong because the damage that it inflicts on a democratic society far exceeds any harm that HSS research is capable of causing to individuals' (Dingwall, 2008, p. 1).

This issue of proportionality in terms of the constraints placed on the conduct of research through sometimes burdensome procedures for gaining ethical approval in relation to the risk of harm remains a contested point for some. Jacqui Gabb (2010) notes that there has been a 'notable increase' in the ethical regulation of qualitative research in the humanities and social sciences. She goes on to outline how –

'Emergent procedures of regulatory control have resulted in systems of governmentality that locate the researcher and the research subject in positions of potential conflict, engaged in a dualistic relationship that requires mediation. In this combative scenario 'certified ethicists' have become designated as the gatekeepers of research, presiding over ethics committees that are designed to protect innocent research subjects from the 'barbarian researcher' who is always trying to take advantage in some way' (Gabb, 2010, p. 466).

In the same paper, Gabb (2010) summarises her position in a way that resonates with my own feelings on the topic when she states that –

'I am not advocating that we cast aside ethical procedures and ride roughshod over those whose lives are shared with us. What I am suggesting is that we may have overstepped both what is required of us and what participants reasonably expect' (Gabb, 2010, p. 475)

It seemed to me that both the participants in my more recent research as well as my doctoral research cared most of all about their relationship with me and how I interacted with them above the procedures I had gone through prior to starting the research. The contested wording on page three of my participant information sheet certainly seemed of greater interest to the committee I faced in a London hospital than it was to the people I interviewed. This is not to suggest that we should fail to thoroughly scrutinize our actions as researchers but the 'combative nature' of the situation as described by Gabb (2010) is indeed at odds with how relationships have been formed and developed with my research participants. Perhaps an appropriate note to finish this discussion on ethical considerations comes from Carolyn Ellis who urges researchers to – '... act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences' (Ellis, 2007, p.3).

Phenomenology

Phenomenology has been described as -

'An attempt to bring philosophy back from abstract metaphysical speculation wrapped up in pseudo-problems, in order to come into contact with the matters themselves, with concrete lived experience' (Moran, 2000, p xiii)

Phenomenology is – according to Michael Crotty – a 'simple enough concept' (Crotty, 2003, p. 78). It is essentially 'the science of the phenomenon' (Lewis & Staehler, 2010, p.1). It is based on engagement with the 'phenomena in our world' and the process of

making ‘... sense of them directly and immediately’ (Crotty, 2003, p. 79). The movement was launched with Edmund Husserl’s ‘battle cry’ of ‘back to the things themselves!’ (Crotty, 2003, p. 78). Husserl’s concern in developing a ‘bold and radical’ way of doing philosophy was based on a need to bring philosophy back from ‘abstract pseudo-problems’ to a focus on ‘lived experience’ (Moran, 2000, p. xiii). Husserl’s phenomenology involves a process of ‘bracketing’ previously held ideas to the best of our ability and letting the ‘phenomenon speak to us at first hand’ (Crotty, 2003, p. 79). Husserl advocated what he called the ‘eidetic reduction’ (Smith et al. 2009). This was a process whereby each reduction –

‘... offers a different lens or prism, a different way of thinking and reasoning about the phenomenon in hand. Together, the sequence of reductions is intended to lead the inquirer away from the distraction and misdirection of their own assumptions and preconceptions, and back to the towards the essence of their experience of a given phenomenon’ (Smith et al. 2009, p. 14).

It is of course not possible to bracket out the ‘taken-for-granted world’ and come to each phenomenon as a researcher with completely fresh eyes. It is not possible but attempting to do so is useful. Kathryn Ahearn (1999) suggests that bracketing is in fact part of a reflexive process and that they are ‘fruit from the same tree’ (Ahearn, 1999, p. 410). While I was not able to suspend my previous understanding and experience it was useful to try to interrogate the ideas I brought with me to the situation. I was surprised by what I learned about my participants through the research and this is perhaps a good measure of success. While I had often experienced conflict with my participants in my day to day practice prior to the research – as outlined in the ethnographic fiction included in this thesis – they revealed a desire to please others in the interviews I conducted. I would argue that when the researcher learns something new and novel within a familiar research situation it suggests a process of exploration and investigation rather than mere description.

There are a number of significant writers and philosophers who have contributed towards the development of the phenomenological movement and inevitably there is a considerable diversity concerning the central issues and opinions regarding how

phenomenology can be applied to research (Finlay, 2009). Martin Heidegger – Husserl’s student – followed in his footsteps but questioned Husserl’s version of phenomenology and considered it to be ‘too theoretical, too abstract (Smith et al. 2009, p. 16). His most well-known concept was ‘Dasein’ – literally, ‘there-being’ and it refers to the ‘... uniquely situated quality of ‘human being’ (Smith et al. 2009, p. 16). Heidegger’s ideas are complex and it has been suggested that he ‘... does not write for beginners in philosophy’ but assumes his readers have ‘... wrestled with the history of Western thought’ (Polt, 1999, p. ix). It is not possible to explore the subtleties of Heidegger’s work within this context and it is perhaps more pertinent to consider Heidegger’s contribution towards the development of IPA as a methodological approach. Smith et al. (2009) suggest that what IPA researchers can take from Heidegger’s work is an awareness of that our ‘... being-in-the-world is always perspectival, always temporal, and always ‘in-relation-to’ something (Smith et al. 2009, p. 18). This sense of connection, of situation, of ‘existence in context’ sits well with other theoretical influences that have been brought to bear on this research through the use of Bourdieu’s concept of ‘field theory’.

When outlining the development of phenomenology and how the work of particular thinkers has influenced the development of IPA, Smith et al. (2009) also outline the influence of Maurice Merleau-Ponty and Jean-Paul Sartre. They compared Heidegger’s concern with ‘worldliness’ with Merleau-Ponty’s emphasis on the ‘embodied’ nature of our relationship with the world (Smith et al. 2009, p. 18). This focus on ‘embodied’ experience is particularly interesting in relation to my research because epilepsy is a condition that creates a highly unreliable body – one which may lapse into unconsciousness or cause sensation or involuntary movements. Smith et al. (2009) argue that Sartre takes Heidegger’s concepts of ‘worldliness’ further, developing the point in relation to personal relationships – ‘... we are better able to conceive of our experiences as contingent upon the presence – and absence – of our relationships to other people’ (Smith et al. 2009, p. 20). This relates once more back to a concept from Bourdieu. We are ‘agents’ in a ‘field’ that is occupied by other ‘agents’.

Within her paper on phenomenological research Finlay (2009) asks the question of whether phenomenology is in fact science or art. It would seem to me that it is more or less scientific or artistic depending on how it is conceptualized and expressed. Finlay (2009) quotes van Manen (1990) who suggests that phenomenology is a 'poetizing project' that tries to create '...an incantative, evocative speaking, a primal telling, wherein we aim to involve the voice in an original singing of the world (Finlay, 2009, p. 14). She contrasts this with Giorgi (1997) who calls for phenomenology to be '... systematic, methodical, general, critical' (Finlay, 2009, p. 14). I would argue that phenomenology is able to inform many different kinds of research approaches. Wertz (2005) characterises it perhaps more poetically when he suggests that phenomenology is a '... lowhovering, in-dwelling, meditative philosophy that glories in the concreteness of person world relations and accords lived experience, with all its indeterminacy and ambiguity, primacy' (Wertz, 2005, p. 175).

Interpretive Phenomenological Analysis

Eatough & Smith (2006) suggest that IPA has both a 'long and a short history' (Smith & Eatough, 2006, p. 324). The long history has been outlined in the above account concerning the development of the phenomenological movement from the work of Edmund Husserl onwards. The short history of IPA concerns the more recent work of a number of psychologists who have developed concepts taken from phenomenology into a methodology as a means to take 'important theoretical ideas' and attempt to '... operationalise one way of working with those ideas' (Smith et al. 2009, p. 4). In a 1996 paper, Jonathan Smith argued for the use of IPA as an approach that has a role to play in health psychology research, although he recognised that the term IPA was not a 'consensual label' that was '... utilised and recognised by a single school of researchers' (Smith, 1996, p.261). Since this time however it would seem that IPA has grown in popularity. Although developed in the field of health psychology, proponents of the approach suggest that IPA is useful across a broad range of disciplines and subject areas (Smith et al. 2009, p. 5).

IPA has provided a practical framework with which to approach my research and after gaining experience using this methodology I would agree that it would be a useful approach for exploring many different topics concerning how people make sense of their experiences. I would however question whether or not this can be viewed – as suggested by Smith et al. (2009) – as a primarily psychological concern that would be of interest to researchers from other fields. After entering the social sciences at postgraduate level and without a grounding in a particular discipline I am perhaps less likely to draw lines and to categorise certain concerns and types of questions as the ‘territory’ of one discipline or another. I would suggest that a concern for how people make sense of their experiences has informed work within a wide range of disciplines and that this could be a question asked with equal relevance in psychology, anthropology, sociology and within many other disciplines including the arts.

There are three primary theoretical influences on the development of IPA (Smith et al. 2009). These are phenomenology, hermeneutics and idiography. While I have already outlined how the phenomenological movement has influenced the theoretical approach taken within this research, it is also necessary to give an account of how hermeneutics and idiography have been influential on the development of IPA and how these concepts have in turn shaped the methodology used in this research.

Hermeneutics

Robson (2002) notes that the original purpose of hermeneutics – the ‘art and science of interpretation’ – was for theologians interpreting the bible for the purpose of making it meaningful for a society that was very different from the one it had been written for (Robson, 2002, p. 196). Likewise, the use of hermeneutics in modern day social science research is very different from the initial use in relation to interpretations of the bible. Crotty (2003) charts the development of modern hermeneutics through the work of Schleiermacher, Dilthey, Gadamer, Heidegger and Ricoeur and suggests that ‘... our debt to the hermeneutic tradition is large’ (Crotty, 2003, p. 111). It is a tradition that focuses on attempts to ‘read’ not only written texts – such as the Scriptures – but also

unwritten sources such as ‘... human practices, human events, human situations’ (Crotty, 2003, p. 87). Gadamer (1975) suggests that the work of hermeneutics ‘... is not to develop a procedure of understanding but to clarify the conditions in which understanding takes place’ (Quoted from Schwandt, 2003, p. 304). As noted, this concern for meaning-making in context resonates with other elements of this thesis – particularly in the application of Bourdieu’s field theory. The interpretations I brought to bear on the research were related to my understanding of the context in which it was conducted.

The IPA researcher – like many other kinds of researcher - is caught within the ‘hermeneutic circle’; attempting to interpret the way in which the participant in their study is also trying to make sense of their experiences (Smith & Osborn, 2003). IPA requires an approach that is both phenomenological in that it is an attempt to get as close as possible to the personal experience of the participants and also hermeneutic in that it recognises that this inevitably involves an ‘... interpretive endeavour for both participant and researcher’ (Smith et al. 2009, p. 37). Hermeneutics is, then, the means by which the phenomenon is explored and comes to be known. The phenomenon explored in this study is the transition to adulthood for young women with epilepsy and learning disabilities. The process of interpretation undertaken in this research has involved a multifaceted analysis of the ways in which they represented their experiences and the words and expressions they used to tell their stories. It is my interpretation of their representation of their experiences which have initially been filtered through their own interpretation. My participants would possibly not phrase it in this way however. They would mostly likely refer to the research process as ‘talking’.

Idiography

The third theoretical influence on IPA is a concern with the particular, with the idiographic. This reflects – according to Smith et al. (2009) – a concern with developing a sense of detail and a commitment to ‘... understanding how particular experiential phenomena (an event, process or relationship) have been understood from the

perspective of particular people, in a particular context' (Smith et al. 2009 p. 29). Epilepsy research, reflecting a medical bias and concern with treatment and management, typically features a sample that is sufficient to allow generalisation. This is the purpose of most research in this field as the focus is on finding a way to identify and/or alleviate symptoms. As argued throughout this thesis however there should be a space for consideration of the particular and the personal within the research literature as it relates to epilepsy.

While it is possible to answer questions concerning the efficacy of drug therapies with a randomised controlled trial it is necessary to ask questions and explore in a different way if we are to understand more about living with epilepsy. Case studies appear to feature in the medical literature in relation to interesting or unusual cases – patients presenting puzzling symptoms, conditions masquerading as other conditions - which would be of interest to doctors and could perhaps provide helpful learning points. I would argue that like the medical case study there is value in the exploration of the lived experiences of people who have epilepsy in a way that is particular and personal – idiographic. It is the particular and the personal that lends meaning to the work of scientists who endeavour to help to treat and manage people with epilepsy. As suggested by the psychiatrist Lisa Francesca Andermann (2000) in her review of epilepsy from a social science perspective –

'The medical and surgical literature provides the ever-expanding body of knowledge from which to proceed, with the goal of helping to control seizures and improve lives. What should not be forgotten in this process is the inclusion of the subjective experience of epilepsy, not only the illness itself, but also of its treatment. This is what gives meaning to the entire endeavor, and should not be overlooked' (Andermann, 2000, p. 174).

Data Production & Analysis

Tim May (2003) suggests that -

'Data are not collected, but produced. Facts do not exist independently of the medium through which they are interpreted, whether it is an explicit theoretical model, a set of assumptions, or interests that have led to the data being collected in the first instance' (May, 2003 p. 28).

May's (2003) conceptualisation concerning how data are 'produced' as opposed to 'collected' has been useful when conceiving how I could usefully approach the process. Semi-structured interviews were used in the first instance to generate data for this research. I had compiled prompt sheets which included key questions related to perceptions of adulthood and also a number of other questions – about family relationships, asking for reflections on educational experiences, questions regarding my participants' perceptions concerning the situation in which the interviews were being conducted. Some of the questions were directly related to the transition to adulthood and ideas about adulthood and some were intended to generate talk. What I soon found was that if I encouraged my participants to talk openly and then referred back to the prompt sheets they had often covered the essential concerns of the research in the course of our 'conversation'. This was more or less successful depending on the ability of my participants to engage with the process. Some were more talkative than others.

The interviews were transcribed and observations made during this process were an initial stage of the analysis. The data analysis was undertaken in a series of readings, returning to the transcripts again and again, reading one and moving to another, moving back and forth iteratively, reading one transcript in the light of another. IPA is a creative process (Smith et al. 2009) and challenging in the initial stages – in my experience – for a novice researcher as it involved generating a lot of ideas and thoughts about the data that at the time did not seem sufficiently profound to sit with my preconceived notion concerning how the analysis should be achieved. 'Letting go' and writing freely was the first step to engaging with this process.

I arranged the transcripts into tables with three columns, with the interview data in the central column. I wrote a long list of observations in the right hand column, commenting on the content of what my participants were saying to me, the language they used, the way they spoke, the attitudes and ideas that they seemed to be revealing. What

gradually emerged from this process was a list of themes. Janice Morse (2008) has distinguished between 'categories' and 'themes' by suggesting that the former are a collection of data sorted in the same place to help the researcher describe the characteristics of the category, whereas a 'theme' is a –

'... meaningful "essence" that runs through the data. Just as a theme in opera occurs over and over again, sometimes in the foreground, sometimes in the background, and sometimes co-occurring with other tunes, so does the theme in our research. It is the basic topic that the narrative is about, overall' (Morse, 2008, p. 727).

This was a useful way to conceptualise what I was looking to find and establish through the process of the analysis. Within and between the transcripts, I noticed that certain ideas were appearing regularly. Thoughts and ideas were noted in the left hand column of my table. Using the terms suggested by Smith et al. (2009) in relation to IPA analysis, I was using the 'subthemes' noted in the right hand column to create the 'superthemes' that were outlined in the left hand column. This was not a linear process however and subsequent readings were used to develop the themes.

The final stage of the analysis was to try to fit the themes into a conceptual model, working out the relationships between these ideas and how they built towards an understanding that would begin to make sense of the research questions. It was a slow process and initially I struggled to see how these different elements fitted together. It took time – and a considerable amount of notepaper – to complete the trial and error process of drawing lines and arrows and making notes to try to fit the themes together in order to create a coherent picture. Once the final version of the conceptual model was completed I reviewed the interview transcripts again in order to assess if the findings reflected what my participants had told me during the interviews. As noted, IPA is a methodology that is underpinned by hermeneutics and as such it essentially involves an act of interpretation. I have not told the only version of the meaning of adulthood for my participants but one which I ultimately found to be credible in light of my understanding of the ways in they interpret their experiences.

The account I have given above is somewhat mechanical and I have been conscious of the need to provide sufficient detail to give a clear idea concerning the steps that were

taken in order to generate and analyse the data. This is a response to misgivings about qualitative research that is represented as if the 'collection' of the data and the analysis could be explained with the simple statement concerning philosophical and methodological influences. It has been suggested by Hunter et al. (2002) that there is – '... magic within the method of qualitative data analysis' (Hunter et al. 2002, p. 388). They note however that although – 'Literature demonstrate the difference between factually reported, dry results and the insight that occurs in elegant qualitative studies... little is written about how this elegance occurs' (Hunter et al. 2002, p. 388). How to move beyond the words on the page towards an idea of what they may mean is not always clear for a novice researcher.

This account has outlined the difficulties and the time consuming nature of the data production and the phenomenological analysis and what also needs to be emphasized is that there were moments of enjoyment that made it seem a worthwhile process that had the potential to capture important insights into the lives of the young women who participated in this study. The difficulties but also the rewards of the research process are referred to by Behar (1996) when she suggests that –

'At the end of the voyage, if you are lucky, you catch a glimpse of the lighthouse, and you are grateful' (Behar, 1996, p. 3).

Bourdieu's Key Concepts

The next part of this chapter on methodology concerns the use of Bourdieu's 'key concepts' as a theoretical framework for the research described in this thesis. I have briefly outlined and defined the particular concepts that have been used within this thesis. I have taken the term 'key concepts' from Grenfell's (2008) work on Bourdieu, in which he described these concepts as Bourdieu's 'thinking tools'. I have used Bourdieu's work as a kind of 'theoretical toolbox', adopting concepts that have been useful as a 'lens' through which to consider the 'field' in which the research was conducted, the ways in which 'agents' who operated in this field acquired different types

of 'capital' and the development of distinctive forms of 'habitus'. Wacquant (1992) describes a (Bourdieuian) field as -

'... simultaneously a space of conflict and competition, the analogy here being with a battlefield, in which participants vie to establish monopoly over the species of capital effective in it – cultural authority in the artistic field, scientific authority in the scientific field, sacerdotal authority in the religious field and so forth' (Wacquant & Bourdieu, 1992, p. 17).

The species of capital – as detailed within the discussion chapter in this thesis – that the agents (participants) in the field (research situation) appeared to be most concerned with acquiring was a type of capital I have termed the 'capital of adulthood'. Bourdieu's definition of capital is very wide and includes material objects (which have symbolic value) as well as 'untouchable' but 'culturally significant' attributes like status and prestige that have value within the context of a situation wherein they are considered to be valuable (Maher et al. 1990, p. 13). As outlined in the chapters that report on the findings in this thesis, the young women in my study appeared to place a particularly high value on developing and displaying the specific behaviours they associated with being an adult and the privileges and advantages adult status would bring. The ways in which they perceive and conceptualise adulthood are linked to the distinctive features of their situation as young women with epilepsy and learning disabilities within a residential special college. This has been outlined within the discussion chapter in this thesis in relation to Bourdieu's concept of 'habitus'. Wacquant, quoting Bourdieu (1977), suggests that habitus is -

'... a system of lasting and transposable dispositions which, integrating past experiences, functions at every moment as a matrix of perceptions, appreciations and actions and makes possible the achievement of infinitely diversified tasks' (Wacquant & Bourdieu, 1992, p. 17).

Bourdieu conceptualises habitus as 'feel for the game', an 'embodied sense of the world and one's place in it' that is 'internalised in individuals through early socialisation in the family or primary group' and this disposition is something that people carry as they enter new settings (Sallaz & Zavisca, 2007, p. 25). The young women who participated in my

study revealed a ‘feel for the game’ that suggested the game in question was one which involved strict rules concerning how they should behave in order to achieve the capital of adulthood. As later outlined, the different elements of a particular ‘code of behaviour’ that appears to be deemed necessary to be recognised as an adult have been arranged into a conceptual model.

The rationale behind my decision to use Bourdieu’s work was that it provided a useful way to frame the interpretation I had taken from the phenomenological analysis in the context of the research situation. It provided a ‘next step’ in terms of how to conceptualise the findings in a way that explained their relationship to the research situation. As noted, Bourdieu was concerned with ‘reflexivity’ and what he later termed ‘auto-analysis’ (Reed-Danahay, 2005, p. 4). He issued an ‘invitation to reflexive sociology’ (Wacquant & Bourdieu, 1992) that encourages the researcher to consider the influences of their personal circumstances and situation that are brought to bear on the research process. Using both a phenomenological methodology that has involved engagement with the ‘hermeneutic circle’ lends itself to this reflexive stance and the use of Bourdieu’s concepts in conjunction with phenomenology has proven useful in terms of providing a theoretical framework for the findings. Bourdieu’s call for reflexivity is answered in part through consideration within the discussion chapter concerning my own habitus as a researcher and how this has influenced the interpretation of the findings.

Ethnography & Ethnographic Fiction

Ethnography n. Scientific description of races of men (Concise Oxford Dictionary, 1977 edition).

Ethnography (from Greek ἔθνος *ethnos* = folk/people and γράφω *grapho* = to write) is a qualitative research design aimed at exploring cultural phenomena (Wikipedia, 2012).

'A meeting of teachers from Oxford, Cambridge and London was held to discuss the terminology of our subject. We agreed to use "ethnography" as the term for descriptive accounts of non-literate peoples' (Radcliffe, 1952).

Ethnography is the study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings (Brewer, 2000, p. 10).

Ethnography is about telling a credible, rigorous and authentic story. Ethnography gives voice to people in their own local context (Fetterman, 2010, p. 1).

In common with all of the theoretical and methodological influences that have shaped this thesis, there are varying definitions that can be found concerning ethnography. The history of the discipline is reflected in the above quotations. The second-hand dictionary that sits on my desk happens to be the 1977 edition of the Concise Oxford Dictionary and the definition it gives of ethnography as the 'scientific description of races of men' evokes the origins of ethnography in the 19th century practice of white men travelling to foreign lands and attempting to create scientific descriptions of the 'primitive' cultures they encountered. It is difficult to relate to this definition of ethnography in terms of the research I conducted. The literal meaning of the word ethnography – writing about people – suggests a broad interpretation of the term that opens the field to include work in a wide range of contexts and disciplines. In order to locate the work I am doing within the ethnographic tradition it is necessary to draw on contemporary writers who share a concern for studying the lived experience of people 'in context'.

The research described in this thesis reflects Tedlock's (2003) assertion that ethnography is an '... ongoing attempt to place specific encounters, events, and understandings into a fuller, more meaningful context (Tedlock, 2003, p. 165). Wolcott (1995), in the title of his book, refers to ethnography as a 'way of seeing' and as a methodological tool it became a 'way of looking' at situations and a 'way of asking' particular questions. I had always been curious about the perceptions of the young people I worked with during my time as a carer but taking on the role of researcher meant I was then tempted to try to delve into their experiences on a different way –

asking for opinions and explanations in a way that went further than our usual exchanges. When I tried to do this over the breakfast table or in passing conversations however I was met with giggles, shrugs and admonishment from one young woman who wanted me to 'stop being weird'.

Richardson (2000) refers to the work of some ethnographers who wish their work to be both 'scientific' and 'literary' and positions herself quite firmly within this camp. I also share this desire. Richardson suggests that some ethnographers –

'... recognise the historical split between scientific and literary writing that emerged in the 17th century as unstable and mutable. We have welcomed the blurring of genre, the complexity of writing, the shaggy boundaries between "fact" and "fiction", "subjective" and "objective", "true and "imagined". We smile at the oxymoronic genre namings: creative nonfiction; faction; ethnographic fiction; the non fiction novel; and true fiction' (Richardson, 2000, p. 253).

My own research fits within this tradition of 'boundary work' between fact and fiction, science and art. What I am proposing is that the use of an ethnographic approach and ethnographic fiction in particular is able to contribute towards a better understanding of the research situation and the research questions. The 1977 edition of the Concise Oxford Dictionary uses the words 'feigning' and 'counterfeit' to define 'fiction' and 'fictitious'. I would argue that the use of ethnographic fiction in the context of this research is useful in revealing more about the research situation and that rather than concealing and presenting a false version of events it enhances understanding and offers insight for the reader. I am not suggesting that ethnographic fiction is the only way to write about research in a way that is engaging and focused on capturing 'lived experience' but it is one way in which this can be achieved while also meeting the criteria of 'not being boring' (Richardson, 2003). Darrel Caulley (2008) states that creative non-fiction is 'never boring' and I would certainly not endorse this view as it suggests that the execution of the form is of no consequence once a particular methodological stance has been taken. I would argue instead that the use of creative ways to represent research findings – such as ethnographic fiction - offer a potential means to create a work that resonates with readers in a different and evocative way – if it is done well.

Atkinson et al. (2001) remark on the diverse nature of the practice of ethnography when they propose that -

'Contemporary ethnographic research is often characterised by fragmentation and diversity. There is certainly a carnivalesque profusion of methods, perspectives and theoretical justifications for ethnographic work' (Atkinson et al. 2001, p. 2).

I hope not only to belong to the tradition of ethnography but also to contribute towards the 'carnavalesque' nature of work in this field. It is my intention that the work I have created should not only sit within the ethnographic tradition but that it should also provide a novel and insightful way to explore and examine the experiences of the young women in my study.

'Like standard ethnography' – wrote Langness & Frank in 1978 – '... ethnographic fiction has as a conscious and integral part of its goal the accurate description of another way of life, but unlike ordinary ethnography it does this through character and plot (Langness & Frank, 1978, p. 18). This is a useful description concerning how I have tried to use ethnographic fiction within this thesis. I have used character and plot to try to create an 'accurate description' of the research situation. In using ethnographic fiction to write about research I am joining a long tradition.

Nancy Schmit, writing in 1984, notes that she is aware of at least sixty anthropologists who have written fiction based on their fieldwork (Schmit, 1984). She suggests that – 'Anthropologists have been writing ethnographic fiction as long as they have been writing ethnography' (Schmit, 1984, p. 11). She also refers to ethnographic fiction as '... anthropology's hidden literary style' and states that 'Some ethnographic fiction has been hidden, or perhaps more accurately swept under the rug, by anthropologists who felt that it was inappropriate for consideration as ethnography' (Schmit, 1984, p. 11).

One example Schmit gives of an anthropologist who struggled in her lifetime to have her fictional work recognised as worthy of attention was Zora Neale Hurston (1891 – 1960). A Black American woman who was a folklorist as well as a novelist, playwright and short story writer, Hurston used the stories she gathered through her work as an

ethnographer as a basis for her ethnographic fiction, collecting what she referred to as 'big old lies' – ie folktales (Walker, 1980, p. xi).

Another example from within the tradition of anthropologists who also wrote in fictional forms is the Native American ethnographer Ella Cara Deloria who produced ethnographic works such as 'Speaking of Indians' (1944). She also wrote a novel, 'Waterlily', in 1947 for the purpose of describing Sioux culture, particularly focused on the role of women within this society. The novel did not find a publisher within Deloria's lifetime however and it was published posthumously in 1988, 18 years after the writer's death. Of this novel she said –

'Only my characters are imaginary... the things that happen are what the many old women informants have told me as having been their own or their mothers' or other relatives' experiences. I can claim as original only the method of fitting these events and ceremonies into the tale... [It] reads convincingly to any who understand Dakota life... And it is purely the woman's point of view, her problems, aspirations, ideals, etc' (Quoted by Susan Gardner in the introduction to *Waterlily*, 2009 edition)

This ambition to create work that would 'read convincingly' for anyone who knows the field (culture) I am describing in my research is one that I recognise and share. I want for my account of the research to 'ring true' and to also resonate emotionally with the reader. Kay Inckle (2010) describes ethnographic fiction as a 'methodology of the heart', taking her inspiration from Pelias (2004) and his book of this title. She writes about using ethnographic fiction as a way to speak 'embodied truth' in her paper about researching body-marking practices (Inckle, 2010). Inckle draws on a feminist tradition, with concerns for issues such as power and equality, means of representation and the need for ongoing self-reflection (Inckle, 2010). Inckle quotes Smith (2002), who suggests that ethnographic fiction –

'... helps us to think with stories; and to invite the reader-as-witness to morally breathe and share a life within the story-telling relation... it is a powerful means of conveying complexity and ambiguity without prompting a single, close convergent reading... The genre becomes an opportunity and space where one may relinquish the role of the

declarative author persuader and attempt to write as, and be represented by, an artfully-persuasive storyteller' (Smith, 2002; cited in Inckle, 2010, p. 39).

Ethnographic fiction has been used in part within this thesis as a means to attempt to produce the 'accurate description' referred to by Langness and Frank (1978) but I am concluding with the suggestion, as noted above, that ethnographic fiction is also a way to convey the 'complexity and ambiguity' of the situation and this is in a sense a part of that 'accurate description. I have used ethnographic fiction within this thesis as a means to represent the findings in part and in doing so I have joined a long and – it seems – colourful tradition of ethnographers who have also written creatively about research and the cultural field in which it was conducted.

Writing as a Method of Inquiry

Perhaps even more compelling than Richardson's (2003) call for the use of 'writing as a method of inquiry' is the demonstration Helen Bowstead (2011) gives concerning how this works in practice. In her 2011 paper, Bowstead has written a reflective account of her work supporting an undergraduate student with academic writing as a study skills coordinator. It is a moving and engaging account and it resonates with how I conceptualise this process of 'inquiring through writing'. Her paper is poetic, personal and unpretentious as it lays open the development of ideas. Self-doubt and the often 'untidy' process of refining thoughts and opinions are not hidden behind a veneer of seamless academic writing. Writing as a way of finding out what I think is a long-ingrained habit that was reinforced as an undergraduate by a creative writing teacher – Bill Manhire – who advised that we should 'write what we know' and also 'write what we don't know' (Manhire, 2003).

Richardson (2003) states that -

'I write because I want to find something out. I write in order to learn something that I did not know before I wrote it. I was taught, however, as perhaps you were, too, not to write until I knew what I wanted to say, until my points were organized and outlined (Richardson, 2003, p. 501).

Like Richardson, I write to find out what I think and the work I create in any form grows from the faltering attempts at opening lines. I started Evie's story in 2007 as a response – outlined in the opening of this thesis – to the way in which the participants in my study went 'missing' when I started to transcribe the interviews I did with them. I returned to Evie's story repeatedly as the themes began to emerge from the data analysis. Sometimes the process went in the opposite direction and it was through reflecting on Evie and the experiences I have had caring for young women like her that informed my understanding of the themes that were surfacing.

Wolcott (2002) quotes Geertz, who suggests that –

'This backwards order of things – first you write and then you figure out what you are writing about – may seem odd, or even perverse, but it is, I think... standard procedure in cultural anthropology' (Wolcott, 2002, p.97)

It is a point to which Wolcott adds - 'I'll hazard that it's a standard procedure in most qualitative inquiry. Discovery is our forte' (Wolcott, 2002, p 97). This way of working was one which came naturally but this does not suggest that the work came easily. I wrote endless earlier drafts of the chapters within this thesis. As detailed within the ethnographic fiction included in this thesis, there were late nights spent following a great number of tangents. I wrote thousands of words that were eventually consigned to the virtual wastepaper basket.

Although described in somewhat negative terms – due to the time intensive nature of this process - it was actually following tangents and exploring topics that were not included in the final draft of this thesis that was instrumental in reaching this stage. Writing strategies are individual and those engaged with academic writing will undoubtedly employ different means to develop their work and their ideas. I have used writing as a method of inquiry, cultivating and refining my ideas to the point where I am ready to 'nail my colours to the mast'. Perhaps the most challenging aspect of this process is settling on a conclusion.

Juxtaposition of Accounts

As noted above, the process of conducting the analysis shaped the writing of the fictional account and reflecting on elements of the research situation and the process through writing Evie's story in turn helped to clarify the themes and ideas that emerged from the phenomenological analysis. The purpose in placing these two different types of accounts alongside one another is that one will enhance the reader's understanding of the other. It is hoped that each will allow a different but complementary way of reading the findings that have come from the research. The purpose of this approach is to aim for depth of understanding on a level that is different from what would have been possible with only one type of account. Without the phenomenological analysis, Evie's story might be read as interesting but the connection to the findings would not be clear. By exclusively presenting the phenomenological analysis the reader would not have been allowed insight into the research situation and the factors that had been brought to bear on the development of the findings.

One of the primary influences on the way in which this thesis has been written is the work of Margery Wolf (1992) and her account of anthropological research undertaken in Taiwan in the 1960s. In a 'Thrice Told Tale' Wolf initially presents a fictional account of a research situation, in the field in rural Taiwan. In a separate chapter she provides the original field notes. The third and final telling of this tale is an essay reflecting on feminist theory, historical developments in the field of anthropology and the practice of ethnography. It was a particularly useful text to encounter early in the process of developing this thesis as it emphasises that the research and the research situation can usefully be represented in a number of different ways. In his poem 'Thirteen Ways of Looking at a Blackbird', the poet Wallace Stevens suggests that there are multiple ways to consider the appearance and meaning of a blackbird. Researchers likewise have a number of choices when it comes to how they will approach a research situation and how they will represent what they find. An argument put forward within this thesis is that they need not be restricted to one way of telling the story.

Identifying the Methodological Literature

The process of finding a 'place to stand' (Dunne et al. 2005) with regard to research methodology was initially guided by the taught components of the Doctor of Social Work Programme and general introductory texts such as Colin Robson's 'Real World Research' (2002) and 'Research Methods in Education' (Cohen et al. 2000). I was also offered a 'world of possibilities' in my education as a researcher through the Sage Handbooks of Qualitative Research (Denzin & Lincoln, 2003,a,b,c) and they have continued to be useful throughout my education as a researcher. I also made use of Creswell's (1998) 'Qualitative Inquiry and Research Design', Crotty's (2003) 'Foundations of Social Research' and 'Understanding Social Research' (McKenzie et al. 1997) while attempting to settle on a methodological approach that would sit well with my ambitions to conduct research that would include the voices of young people with epilepsy.

My decision to adopt IPA came about however following a chance conversation with a former colleague who had also worked at the epilepsy centre where the study was conducted and who was familiar with the situation and the type of young women who would be participants in my study. She had used IPA in her own doctoral research (published as Gupta et al. 2007) and was able to provide guidance concerning conducting a study using IPA and the challenges and opportunities that this methodological approach entailed.

Discussions with my supervisor in the summer of 2010 concerning the need to answer the 'so what?' questions that soon developed during the process of analysis led me to consider the ways in which the findings could be theorized and this in turn resulted in the decision to use Bourdieu's key concepts as a means to interrogate the data. Although I had been introduced to Bourdieu earlier in the doctoral programme, it was only at a later point that I began to appreciate that his work offered me a useful way to theorize and explore further. After gaining more of an understanding of the 'theoretical toolbox' that Bourdieu offered me I also began to appreciate that his concepts not only gave me the means to make sense of what I was finding in my research but they were

also a useful way to appreciate the cultural field and political landscape of my work situation in a way that makes even problems seem interesting.

Literature Search & Review

Chris Hart (1998) identifies at least eleven aims for a literature review. They include distinguishing what has been carried out previously and what remains to be done and how the research sits within an historical context. It is also a means for the researcher to 'enhance and acquire the subject vocabulary' and 'establish the main methodologies and research techniques that have been used in a particular field' (Hart, 1998, p. 27). He suggests that the review chapter is typically '... an edited down version of the massive amounts of notes taken from extensive reading' (Hart, 1998, p. 20) and in the early stages of the development of this thesis this was the form that the literature review took. Hart's guidance and his emphasis on a systematic, rigorous and critical approach were initially useful for me as a novice researcher as it inspired a thorough way of working when completing the literature search.

In the summer of 2011 I undertook a careful and systematic search of the literature in relation to young people with epilepsy, the transition to adulthood for young people with learning disabilities and the theoretical and substantive literature concerning the transition to adulthood for young people who do not have disabilities. A systematic search was completed over a three week period. This included use of search engines including PubMed, CHINAL, MEDLINE, IBSS, Social Care Online (SCIE), SCOPUS V4, Web of Knowledge and Google Scholar.

However, despite highlighting how important it was to cover all 'relevant work' within a particular field (Hart, 1998, p. 20), Hart appears to fail to recognise that distinguishing relevant from irrelevant work can be exceptionally challenging in the preliminary stages of the research. It was only when my own work was further developed that I was able to begin to form a clearer idea of what kinds of work I need my reader to be aware in order to make sense of the research and place it in context. Hart advises that the literature review is a chapter that should be completed in advance of beginning the research

process (Hart, 1998). Reading widely during the early stages of my research was undoubtedly helpful but this sense of a tidy, linear process in which the literature review is completed as a preliminary stage to the research was not one that I shared and I found that the literature review was – unsurprisingly – no different from any other part of this thesis. It evolved as I shaped and crafted the work further and considered earlier decisions in the light of more developed ideas.

Arlene Fink (2010) describes a literature review as a –

‘... systematic, explicit, and reproducible method for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars, and practitioners’ (Fink, 2000, p. 3).

In common with Hart, Fink emphasises the need for a meticulous approach to the literature review and while this is clearly desirable I started to question the seemingly prescriptive nature concerning how both writers presented what a literature review is and how it should be produced. Identification of which pieces of work are useful based on the results produced from a literature search will be a matter of personal judgment as it will depend on the inclusion and exclusion criteria that are applied and how they are interpreted. The evaluation and synthesis of research findings will likewise depend on judgment and interpretation concerning the relevance and usefulness of different pieces of research and how they contribute to a clearer understanding of any given concern. Both of the writers referred to above seem to suggest – to my mind at least - that there is a singular way to conduct a search and review of the literature.

Presenting an alternative view, Wolcott (2002) rallied against what he called the “Chapter Two” problem. He made the case for a considerably less prescriptive and more tailored approach to the literature review. Although chapter two is traditionally the place of the literature review within a dissertation or thesis, Wolcott argued that –

‘There is no law governing the contents of chapter 2 any more than there is a law that dissertations must be boring... Chapter 2 ought to be whatever you as author want it to be – it’s your story, your research, and you ought to feel free to develop it in the manner that best allows you to accomplish your purposes’ (Wolcott, 2002, p. 96).

As this thesis was introduced by way of ethnographic fiction – one of the key methodological elements of the work – my chapter two is an account of the methodology as this appears to warrant an explanation sooner rather than later. I did not want to leave my reader in the dark concerning the means – methodology - by which we would be reaching our destination by making a diversion into the literature at this stage. It was therefore a logical decision to write chapter two as the methodology. Reading Wolcott's argument did however begin the process of reflecting on the ways in which I could and perhaps should complete the literature review. In relation to the literature review, Wolcott (2002) states that –

'I object strongly to the practice of simply backing up with a truckload of stuff and dumping it on unsuspecting readers, which seems to be what most traditional reviews accomplish. That is more likely to create an obstacle that gets in the way of, rather than paves the way to, reporting what you have to contribute' (Wolcott, 2002, p. 95).

The point noted above refers to an unquestioning adherence to research traditions and serves as a reminder that the literature – theoretical, methodological and substantive – must 'earn its keep' and serve a purpose within the coherent argument presented. An argument that I have found particularly compelling in relation to the literature review is put forward by Smyth & Spence (2012) in a paper which suggests that hermeneutic research calls for a particular type of literature review. They challenge the –

'... taken-for-granted way of the world (that) assumes that there is a way to do a literature review that common to across all methodologies' (Smyth & Spence, 2012, p. 13).

Smyth & Spence (2012) argue that there is a distinctive way to do an hermeneutic review as opposed to a traditional literature review and that within this type of review -

'... there are few rules to follow; rather a way to be attuned. While there will be a focus that influences the scope of the literature to be explored, precious insights may be found in unlikely places. Philosophical and literary texts can bring questions that help make sense of the life situations under exploration' (Smyth & Spence, 2012, p. 14)

They go on to outline how their conceptualisation of ‘the literature’ is wider than accounts of academic research and includes ‘... philosophical texts, fiction, poetry and anything else which engages the reader in a thought-full encounter’ (Symth & Spencer, 2012, p. 14). Literature in this sense is anything that provokes thought – which they describe as a ‘call to thinking’. They outline their own discovery that a literature review can be –

‘... about much more than ‘writing down’; we came to appreciate how important it was that the literature review be engaging to a reader. Our aim was to draw them into thinking, not to present them with a string of ‘facts’. Thus, style, tone and play became important. To call one to thinking is not to ‘tell’ but rather to take the reader on their own journey of seeing, that they too may have their own call to think’ (Smyth & Spence, 2002, p. 21).

Following this path, I began to consider the literature review as a ‘call to think’ and to reflect on how this might be achieved in relation to the literature review in this thesis. Clearly I would need my reader to have some awareness of the broad characteristics of epilepsy research in order to present an argument for an alternative way of conducting research with young people with epilepsy. In the initial part of my review I have therefore given an overview of epilepsy research following a brief summary of the historical, cultural and medical meaning of what epilepsy is and the impact it can have on individuals and families.

The second part of my literature review concerns the transition to adulthood for young people with learning disabilities. I have used this part of the review to ‘look ahead’ to the findings. My participants had identified domestic competence, independence and the consumption of alcohol to be important factors that would allow them to gain adult status. I have therefore considered the literature in relation to these themes, while also noting that although my participants were very clear that behaviours related to these themes were very important to them and their perception of adulthood they seem to be underexplored in the literature. The final part of my literature review is a consideration of theoretical perspectives on the transition to adulthood and how they relate to the findings of this research.

In the final stages of the completion of this thesis I began to conceptualise the literature review as a kind of 'bespoke' element that needed to fit with what I perceived to be the rather eclectic methodological approach that has been taken. Rather than creating an 'annotated bibliography' concerning the reading I have done, I would need to establish the kinds of work that would be useful and the background understanding I need my reader to have in order to make sense of Evie and her story, the phenomenological interpretations of the findings and the theoretical approach I have adopted. I needed to avoid what the anthropologist Karen Brodtkin has referred to as 'genuflection-by-citation, usually to dead old white guys' (Brodtkin, 2011, p. 21) and maintain a focus on creating a literature review that will be a 'call to think'.

Chapter Three – Literature Review – Expectations of Ordinary

Background Noise

Over a period of years, I read a considerable number of books and papers that did not suggest reasons for optimism concerning the future for my participants. In their population-based study Camfield & Camfield (2008) predict the outcome twenty years after childhood-onset epilepsy to be 'death or dependency'. Opportunities for employment may be limited for people with epilepsy due to the attitudes employers have towards employing someone with epilepsy (Jacoby et al. 2005). Having a learning disability will also have a negative impact on employment prospects (Murray, 2003). However, what my participants revealed in the interviews I conducted was an attitude that I conceived of as 'expectations of ordinary'. They expected to get jobs, pay their own way, have families and get married if they wanted. Career ambitions included working with children, joining the police force, becoming a talk show host and one of the participants in this study was having difficulty deciding between becoming a mechanic or a hairdresser. Some of the young people who leave the epilepsy centre where this research was conducted will take undertake employment but it will be in the form of supported employment in the majority of cases.

Griffiths (1994) suggests that 'understanding one's own disability' is important and that young people with learning disabilities are often 'unchallenged and smiled at' when they express unrealistic vocational ambitions (Griffiths, 1994, p. 66). He goes on to suggest that if '... people are patronised in this way and thought of as 'sweet' or 'cute' their dignity is compromised (Griffiths, 1994, p. 66). I experienced mixed feelings when listening to the participants in my study express ambitious aspirations for the future. I liked the way in which what they told me challenged the 'personal tragedy' theory of disability, wherein the 'sufferer' of a chronic condition has a life dominated by struggle and affliction (Oliver, 1986, p 5). The young women in my study did not appear to see this as what the future held for them. However, this point raised questions for me as a

practitioner concerning how we prepare young people such as those in my study for the future and how their expectations should perhaps be managed.

I have introduced this review of the literature with a reflection on the kind of deliberations and considerations that were ‘background noise’ to the process of reading and reviewing the literature. I have done so in order to highlight that the review of the literature was not a straight-forward process of reading widely and making some notes. There were decisions to be made concerning how I approached the review – as noted in the methodology chapter – and there were also personal feelings related to my practice experience that influenced how I interpreted what I was reading and made sense of the literature as a whole.

What is Epilepsy?

In his medical and cultural history of epilepsy – ‘The Falling Sickness’ – Owsei Temkin suggests that epilepsy is a condition that involves both ‘physical and psychic symptoms’ and is therefore more open to interpretation than any other disease both as a ‘... physiological process and the effect of spiritual influences’ (Temkin, 1971, p. 3). He goes on to argue that epilepsy has a unique place in medical history as it has been variously characterised as an invasion by ‘gods, demons, or evil spirits’ (Temkin, 1971, p. 3). Epilepsy has been written about in medical science and literature, depicted in art and film and represented in religious terms as either a sign of demonic possessions or of scared powers (Temkin, 1971). It has been suggested that people with epilepsy suffer from a ‘social disease as much as from a neurological disorder’ (Masia & Devinsky, 2000). Writing about epilepsy and identity, Rhodes et al. (2008) suggest that the term ‘epilepsy’ is in fact – ‘... polysemic: it is not just a clinical disorder but a social label’ (Rhodes et al, 2008, p. 385). Epilepsy has a long association with stigma (Scambler, 1989). In relation to epilepsy, the sociologist Graeme Scambler (1989) drew a distinction between ‘felt stigma’ and ‘enacted stigma’ and suggested that stigma is felt by individuals who have epilepsy even in the absence of experiences of ‘enacted

stigma', actions by others which could cause a person to feel stigmatized (Scambler, 1989).

Epilepsy is fact not a 'singular disease entity' but it is rather a '... variety of disorders reflecting underlying brain dysfunction that may result from different causes' (Fisher et al. 2005, p. 470). The International League Against Epilepsy (ILAE) and the International Bureau for Epilepsy (IBE) reached consensus in 2005 concerning definitions for the terms 'epileptic seizure' and 'epilepsy'. They concluded that an epileptic seizure should be defined as a '... transient occurrence of signs and/or symptoms due to excessive or synchronous neuronal activity in the brain' and that epilepsy is a '... disorder of the brain characterised by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological and social consequences of this condition (Fisher et al. 2005, p. 470).

It has been suggested that epilepsy is a pervasive condition in which seizures are only one element (Aicardi, 1998) and Andermann (2000) summarises this when she suggests that –

'Epilepsy is an umbrella term of a panoply of seizure types, auras, epileptic syndromes, memory deficits, postictal confusion, hallucinations, and other associated behaviours as well as electroencephalographic findings' (Andermann, 2000, p. 169).

Childhood epilepsy can have a significant impact on parents and family function. In a systematic review, Speechley & Ferro (2008) concluded that 50% of mothers of children with epilepsy are vulnerable to depression. It has been suggested that the families of children with epilepsy are more likely to experience stress and anxiety (Thompson & Upton, 1992) and that the difficulties are created by the unpredictable nature of epilepsy, potential for injury and associated cognitive and behavioural problems (Rodenburg et al. 2011). One of the themes that has been included in the ethnographic fiction included in this thesis concerns the difficulties in the relationship between Evie

and her mother and this reflects not only my practice experience but also the potential for problems as highlighted in the literature.

As noted, the decision to interview only young women for this research was naturally not inconsequential. Considerations regarding reproductive health and the impact of epilepsy were present in my mind when I asked my participants about having children for example. Major congenital abnormalities in children are associated with exposure to some antiepileptic drugs (AEDs) in the first trimester of pregnancy and little is known about the potential influence of some of the newer AEDs (Perucca, 2005). It is fair to say there was no clear consensus from my participants concerning the desirability of having children but what was significant for me was that none mentioned any health related concerns with regard to an ability to have or care for children. Although the National Institute for Health and Clinical Excellence (NICE) guidelines on 'The Diagnosis and Management of Epilepsy in Children, Young People and Adults' clearly recommend that women and girls with epilepsy should be offered information and counselling on issues relating to contraception and pregnancy it seemed to me that young women with a learning disability – such as those in my sample – may not be given advice and guidance.

It is beyond the scope of this thesis to explore in more depth the social history and implications of the diagnosis and label of epilepsy but it is however important to recognise that this condition has played a significant role in shaping the lives and experiences of the young women who were participants in my study and it is this common factor that had brought them into the setting where the research was conducted. Having epilepsy and the experiences they have had as a result is a part of their 'habitus' and familiarity with this condition after many of years of working with young people with epilepsy is also a part of mine. I have included a brief overview of the condition prior to consideration of the characteristics of epilepsy research in order to provide my reader with context and clarification concerning what epilepsy is and the impact it can have for people who have the condition as well as their families.

Characteristics of Epilepsy Research

With rare exceptions, I would suggest that the literature relating to adolescents and epilepsy can be categorized into seven different areas of interest with an occasional overlap between them. In order to gain an overview of the literature in this very specific area of concern I made the decision that I would attempt to categorise the types of research that are conducted involving young people with epilepsy. I hand-searched the content of five journals which report on research in relation to epilepsy – *Epilepsia*, *Epilepsy & Behavior*, *Epilepsy Currents*, *Epilepsy Research* and *Seizure* - looking specifically for research that focused on young people. It was my observation that researchers appear most concerned with issues relating to 1) neurological functioning 2) psychosocial difficulties 3) treatment and management options 4) service provision 5) Quality of Life (QOL) and 6) stigma. The other category of research to emerge from the process of undertaking this review concerned the negative impact of parenting a child or young person with epilepsy and difficulties in relation to family function.

While it is perhaps not useful in the context of this thesis to further explore all of these categories and delve deeper into the medical literature, the point that I am trying to illustrate is that although all of the concerns outlined above could warrant exploration using a qualitative methodology - and this would potentially be useful for practitioners - few researchers take this approach. Varley et al. (2010) suggest that – ‘Historically, epilepsy research has focused on quantitative methodologies that often fail to capture the invaluable insight of patient experiences (Varley et al. 2010, p. 299).

As noted in a systematic review by McEwan et al (2004), there is now a sizeable literature focusing on QOL in children and adolescents with epilepsy. They conclude that despite this interest in QOL in children in relation to epilepsy, there is a relative scarcity of research that includes an expression of the views of the young people themselves. Commonly, researchers investigating the QOL of young people with epilepsy use proxy opinions from parents and caregivers. McEwan et al. (2004) found only one study - (Ronen et al. 2001) - from the seventeen originally identified that met

their quality criteria in that it included first-hand accounts from the young people themselves.

Taking an overview of epilepsy research through an analysis of 'citation classics', Ibrahim et al. (2012) suggest that the '... fastest growing category within the cohort of highly cited epilepsy research was laboratory investigations' (Ibrahim et al. 2012, p. 765). They suggest that studies involving molecular biology techniques were a particular growth area. As argued in this thesis, it is vital that scientific research into epilepsy is carried out in order to develop treatments and a better understanding of the condition. As suggested however, what gives this process meaning is a better understanding of the individual 'lived experience' of what it means to be a person who has epilepsy.

Qualitative Research with Young People with Epilepsy

Raty and Wilde-Larson (2010) suggest that the literature shows how –

'... previous research on epilepsy has focused on outcomes of medical treatments, patients with intractable epilepsy, quality of life and use of quantitative methods... qualitative research is less frequent and often addresses specific, limited parts of the patient's situation such as difficulties concerning employment, coping techniques and management in relation to life with epilepsy... Fewer studies address the lived experience as a whole' (Raty & Wilde-Larson 2010, p 375).

Although relatively rare, there are studies which include the perspective of young people with epilepsy. Wilde & Haslam's (1996) study highlighted the experience of prejudice, particularly of being teased and bullied at high school. Another example, from 2002 (Hightower et al, 2002) looks at what can be learned from the experiences of children and young people with epilepsy for paediatric nurse practitioners. Research from 2005 (Elliot et al, 2005) again looked at what could be learned from a nursing perspective, concluding that for the young people in their study epilepsy was a barrier to both academic and social pursuits.

Qualitative studies which focus specifically on the experiences and perceptions of young adults with epilepsy are scarce but do exist. One Israeli study uses constant comparison analysis following in-depth interviews (Admi & Shaham, 2007). Their results showed that epilepsy was not central to their participants' everyday lives. They found that the young people in their study were able to adapt and develop coping mechanisms. A second study supports this view and suggests that although the participants in research undertaken in Sweden experienced difficulties and stresses relating to epilepsy – such as limitations on leisure activities, side effects of medication and feelings of being different – they also developed strategies for coping (Eklund & Bengt, 2003).

Wilde & Haslam's (1996) research focuses on the experience of prejudice. However, they also concluded that their participants had well-developed strategies for coping. By looking merely at the subject matter of epilepsy research and young people or by taking a cursory view of the most prevalent themes which run through the literature – psychosocial problems, stigma, impact on QOL – it would seem that a diagnosis of epilepsy is a somewhat damning predicament. Studies which explore the 'lived experience' of being a young person with epilepsy reveal a more multifaceted picture. This is contra to the impression one could take from the literature and could in itself illustrate the argument – as outlined below – that there is much to be gained from a taking a different approach in the study of young people and epilepsy than that traditionally associated with the field.

One significant characteristic of research into the experiences of young people with epilepsy from my perspective is the way in which learning disabilities have been used as an 'exclusion criteria' when conducting qualitative research. Lewis and Parson (2008) noted that when they were recruiting for participants for their study into the educational experiences of children with epilepsy they were contacted by many parents of children with learning disabilities who wanted their child's experiences to be included in the study. However, in this case, the choice of methodology was cited as a reason why this was not possible without – it seems – regard for how the methodology could be

adapted to allow for the inclusion of the experiences of children with epilepsy and learning disabilities in their study.

Likewise, Raty et al (2003) outline exclusion criteria that included intellectual disability in their qualitative study but do not elaborate on their rationale for doing so, suggesting perhaps that it may be taken for granted that young people with a learning disability are automatically unable to contribute to research with a qualitative design. It would seem that some researchers are willing to adapt their research methodology in order to include the experiences of young people with learning disabilities. Wilde & Haslam's (1996) research did include four young people with learning disabilities and used parents to help to facilitate the interviews they conducted.

The study that I carried out recently exploring the educational experiences of children with epilepsy used proxy reports from parents for participants who were not able to engage with the interview process as a way to include them in the study and I was clear that this was one of the limitations of the research – the hermeneutic circle took another spiral when I was looking at the interpretations of parents representing the experiences of their children. While there are additional challenges in carrying out qualitative research with young people with expressive language difficulties this should not – in my opinion – be sufficient rationale for assuming that researchers cannot attempt to overcome these difficulties.

An Argument for Other Ways of Looking

Writing in 1979, West suggested that – 'Orthodox epilepsy research is located within the 'medical model' and imbued with the theoretical and methodological tenets of logical positivism' (West, 1979 p. 719). It is fair to suggest that in the thirty-three years since this statement was made there have not been significant changes. Robson's declaration that it is now widely acknowledged that positivism is a 'god who has failed' is not evident within some circles (Robson, 2000, p. xi). There is perhaps ongoing truth to the comments made by Lather in 1992 that –

'Positivism is not dead, as anyone knows who tries to get published in most journals, obtain grants from most funding agencies, or have research projects accepted by dissertation committees' (Lather, 1992, p.88)

Innovations in the treatment of epilepsy have made a remarkable difference to the quality of life experienced by most people who have the condition. Not only have drug therapies advanced considerably since the discovery in 1939 that phenytoin could be used to treat epilepsy there are a number of other innovations that have improved treatment for the condition. In 1985, hypothesising as a result of animal studies, Jacob Zabara first suggested that stimulation of the vagal nerve could be used to treat refractory epilepsy by disrupting hypersynchronous electroencephalographic activity (George et al. 2000). His hypothesis turned out to be correct and vagus nerve stimulation (VNS) therapy was developed. This involves implanting a device similar to a pacemaker that sends a regular low pulse of electricity to the vagal nerve and it has been proven to reduce seizure rates for some people, significantly in some cases (Degiorgio et al, 2005).

The surgical treatment of epilepsy is possible as a result of the earlier invention – in 1929 – the electroencephalogram (EEG). Recently, work has been undertaken which looks at genetic links to a disposition towards seizures. Although developed initially in the 1920s, the 'ketogenic diet' as a way to treat seizures was not widely used for many years but it is increasingly used to treat some types of seizure disorder (Swink et al. 1997). This is a high fat, low carbohydrate, adequate protein diet that has been shown to be effective for the treatment of children with epilepsy and in some cases it has been shown to be more effective than medication (Cross & Neal, 2008)

The above summary of the development of treatment options for seizure management has been given with the purpose of outlining the significance of work undertaken by medical researchers in the field and highlighting the ongoing need for further research. It is clear that significant numbers of people have benefited considerably from the development of effective treatments for epilepsy and there is ongoing work to be done with the field of genetics now important in investigating causes and treatment for

epilepsy. There are, however, questions relating to the experience of living with epilepsy that would can only be answered through the use of a qualitative methodology.

A particularly eloquent and compelling argument has been put forward by Andermann (2000) concerning the need to broaden our methodological approach when it comes to the study of the epilepsy. She contends that there is considerable benefit to be had in terms of informing medical practice through a better understanding of particular difficulties as experienced by people with epilepsy. Andermann suggests that a social science methodology is required that takes into account ‘... local context as well as social, cultural, and politicoeconomic variables’ (Andermann, p. 172). This resonates particularly well with my research and the use of Bourdieu’s concepts, aiming to contextualise the perceptions of my students and find a theoretical basis for a better understanding of their experiences.

In her paper, Andermann provides a useful overview of the general characteristics of epilepsy research, focused on the biomedical aspects of managing seizures and measuring the impact of the condition. Even when considering QOL issues the focus is on standardised assessments and Likert-scale measures (Andermann, 2000, p 171). There is a note of optimism sounded in her assertion that –

‘The presence of individual voices of people with epilepsy in the growing ethnographic and social science literature can be considered as a starting point from which one can begin to understand the range of people’s experiences with epilepsy. They form an important counterpoint to the growing international body of epidemiological data on this illness which, while of great importance, is measured on a societal level and leaves out the richness of the local experience’ (Andermann, p. 172).

It must be noted however that there does not appear to be a significant body of work created by researchers since these comments were made. The mantle has yet to be taken up in the form of researchers creating a significant body of work. Andermann’s (2000) assertion that it is necessary to view the experiences of people with epilepsy within the context of other aspects of their lives is particularly pertinent to my study, which looks at what it means to be making the transition to adulthood situated in this time, place and environment. As stated, all of the participants in my study have learning

disabilities and the next part of this chapter considers the transition to adulthood for young people with learning disabilities.

The Transition to Adulthood for Young People with Learning Disabilities

As noted, I have used this part of the literature review to 'look ahead' to the themes that emerged from the phenomenological analysis. It was notable that the difficulties I had experienced in terms of identifying literature that included the perspective of young people with epilepsy were also apparent in relation to learning disability research. It has been suggested that the voices of people with learning disabilities have been under-represented in the literature (Mill et al. 2009) as the methods used to conduct research with this population tend to be focused on collecting information *about* rather than *with* them (Reid & Bray, 1998).

In the United Kingdom, researchers such as Dorothy Atkinson, Dan Goodley, Tim and Wendy Booth and Jan Warmsley have led the way in terms of involving people with learning disabilities in research through life history approaches and collectively they argue that it is not only possible but important to conduct research with this population in a way that includes their voices and perspective. They have created the expectation that the voices of people with learning disabilities could and should be heard within the literature. In certain areas however it would seem that other researchers have yet to take up the challenge.

This is apparent in the first theme that has been considered in this review – perceptions and meaning relating to alcohol for young people with learning disabilities. Although it appeared to be a central concern to the young people in my study, it would seem that issues relating to the use of alcohol for young people with learning disabilities have not been addressed in any depth in the literature. In a review of 'what scant literature there is' in relation to alcohol use by people with learning disabilities, Murray Simpkin (2010) suggests that –

'Alcohol is a topic which is perhaps more notable from its general absence from discussion of learning difficulty than its prominence as an issue. It occupies only a very tiny proportion of the not inconsiderable literature on the subjects of either alcohol or learning difficulty. Even a search restricted to work on the social aspects of learning difficulties, social adaptation, integration, independent living etc yields little data on the subject' (Simpkin, 2010, p. 541).

Simpkin (2010) goes on to suggest, in line with my own observations, that the literature that does exist is focused on health education for people with learning disabilities in relation to alcohol (eg Lawrenson et al. 1995; McCusker et al. 1993) or on larger scale statistical studies looking at the patterns or prevalence of drinking problems among people with learning disabilities (Simpkin, 2010). The literature that does exist does not appear to include what meaning people with learning disabilities ascribe to drinking alcohol. Simpkin's (2010) assertion that low levels of alcohol use in the learning disability population are not the result of abstinence but a lack of opportunity (Simpkin, 2010, p. 549) is supported by my practice experience. As noted, there is a scarcity of research in this area and it was necessary to broaden my search to alcohol and adults with learning disability. The meaning of alcohol consumption for young adults with learning disabilities, such as those in my study, appears to be unstudied to date.

The second theme which emerged particularly strongly from the phenomenological analysis was the role of domestic competence in establishing adult status. As outlined within the findings chapter that follows, it would appear that there are specific domestic tasks that my participants felt it would be important to master in order to achieve acquisition of what I have termed the 'capital of adulthood'. In keeping with other considerations in this review, it is my impression that this area of the literature appears to focus on enhancing 'daily living skills' rather than exploring what the development of those skills means to young adults with learning disabilities.

Cronin (1996), in a review of Life Skills Curricular for students with learning disabilities, characterizes much of the research in this area as 'descriptions of programmes' and this was consistent with my impression that there seems to be considerably more concern with the 'problem' of learning disability and how to ameliorate its impact rather than the

'experience'. I was not able to locate any studies which emphasized, as my own did, the significance of domestic competence in terms of acquiring adult status or any work that seemed to focus on these concerns. This is curious when my own practice experience suggests there is a taken for granted view that teaching daily living skills is such an integral part of working with people with learning disabilities.

The third and final theme from the phenomenological analysis that has been considered in this review of the literature is independence. This has been interpreted as 'self-determination' for the purposes of this review as this appeared to be the term which is used in the literature as opposed to independence. There seems to be considerable use of longitudinal approaches in relation to self-determination, following the trajectory in particular from school to work (Durlak & Rose, 1994; Blackorby & Wagner, 1996). Michael Wehmeyer and others in the United States have taken the lead in relation to research about self-determination for young people with learning disabilities (Wehmeyer & Schwartz 1997; Field et al., 2003; Blalock & Paton, 1996).

The ability of a young person to make active choices and achieve self-determination has been linked to successful post-secondary outcomes for adults with learning disabilities (Wehmeyer & Schwartz, 1997). These writers suggest that the theoretical basis of the construct of self-determination is complex, comprised of psychological attitudes within individual as well as environmental opportunities for its practice (Wehmeyer & Palmer, 2003). It may perhaps be assumed that opportunities to develop the psychological attitudes necessary for self-determination might well result from being in an environment which nurtures or encourages them. The extent to which the situation of my participants allowed them to develop self-determination was something that I came to questions as I began to interrogate the data.

Theories of the Transition to Adulthood

The psychologist Jeffery Arnett has suggested that social and especially economic changes in most developed countries have meant that the traditional transition to adulthood is being delayed. This is occurring to an extent that a distinct life phase can

now be identified. He has termed this 'emerging adulthood' (Arnett, 2001). Although it is a convincing argument, I took my lead from my participants concerning how to conceptualise this process and used 'transition to adulthood' instead of 'emerging adulthood' as the term I would use in this thesis. This is because they appeared to understand the process as a progression involving passing from one distinct state – childhood – to another clearly defined state – adulthood.

In a 1997 study, Arnett looked at the attitudes of college students and found that criteria such as finishing education, entering the workforce and getting married were rejected by a large majority of the sample (346 participants) and concluded that the -

'... results suggest that the current generation of young people in American society conceptualizes the transition to adulthood in intangible, gradual, psychological and individualistic terms' (Arnett, 1997, p. 3).

Arnett (1997) found that the predominant criteria for adulthood for the young people in his sample involved aspects of individualism – namely being able to decide on one's own beliefs and values independently from parents. Although, as discussed in the following chapter, my participants in my study revealed a desire for 'independence', for making their own decisions about where they would go and how they would live their lives, it seemed to me that they were expressing the ideals of parents and caregivers in some respects. My thinking with regard to how I conceived the process was undoubtedly influenced by the work of Griffith (1994) who has suggested that young people with learning disabilities may, rather than taking on the role of the 'permanent child', instead slip into 'passive and premature' adulthood, taking on the values of their parents and caregivers. He suggests that -

'Adolescents with severe learning disabilities are often dependent on others for meeting their basic needs; they find it difficult to separate from care givers and often are unable to challenge their views and decisions. A separate individual identity is difficult to achieve in these circumstances (Griffiths, 1994, p. 16)

After considerable reading and further reflection on processes of identity formation it was the work of James Marcia (1966), building on earlier work by Erik Erikson, that

seemed to provide insight into the transition to adulthood for the young women in my study. Marcia distinguishes four 'identity statuses' and links these to the extent to which an individual has explored and resolved issues to do with identity such as the choices that have been made concerning how they will live their lives. The identity status that appeared to 'fit' with what my research was suggesting about the young women in my study was 'foreclosure'. Marcia suggested that 'Subjects in the foreclosure status will endorse "authoritarian submission and conventionality"... to a far greater extent than subjects in other statuses' (Marcia, 1966, p. 552).

I would argue the case that actually what the young women in my study revealed was 'partial foreclosure'. It did surprise me when they revealed attitudes that would more conforming than I was – perhaps – comfortable with, conscious of my own role in their socialisation. However, my practice experience suggests that these are young women who can assert themselves, sometimes very effectively challenging my authority. They had certain common characteristics that have influenced their identity development and they certainly do not fit neatly into Erikson's stages of psychosocial development, with particular ages marking defined stages. They need their own 'theory of adulthood' and this is what I have attempted to create in the conceptual model I have outlined later in this thesis.

Chapter Four – Findings Part I - Alcohol, Adulthood and a Certain Way of Being

Summary of the Findings

This chapter focuses on the themes which emerged from the phenomenological analysis of the data. As noted within the account of the methodology, a process of reading and rereading the transcripts of the interviews was used to generate observations and reflections on the meaning that my participants took from their experiences. Smith et al. (2009) state that –

‘Interpretation in IPA is a form of *amplification* or *illumination* of meaning, which is cued or sparked by a close engagement with the data, and which requires creativity, reflection and critical awareness for its full development’ (Smith et al. 2009, pp. 204 – 205).

This ‘close engagement’ with the data involved taking a reflexive stance and considering why and how the perceptions of my participants were being interpreted in particular ways and what their comments, opinions and assertions meant within the context of their lives. The characteristics common to all of my participants – as young women with epilepsy and learning disabilities in the time and place of the research – are considered in more detail in the discussion chapter in relation to the development of habitus. I have drawn on direct quotations from the interview transcripts in this chapter as a way to open the data to the reader and support the interpretations that have been developed. As well as noting the common themes that have emerged within the process of analysis I have also noted heterogeneity within the sample and the points of difference between some of the views and perceptions revealed by my participants.

Heterogeneity is also referred to in the final part of this chapter as I have considered the meaning that the young women who participated in this study took from their experience of epilepsy. As noted, the perceptions my participants have concerning epilepsy are not the specific focus of this research. It is considered rather as an element which has impacted on the development of habitus for each of the participants. I have included it in

this chapter as a theme that sits apart from the other themes that are explored but which is linked to the wider concerns of the research in terms of factors that have influenced the perceptions and experiences of my participants.

The theme that emerged most clearly from the outset when I started conducting the interviews for this research was an association between drinking alcohol and the achievement of adult status. I have termed this theme 'Alcohol = Adulthood' and noted that it was not merely the consumption of alcohol that seemed important for gaining the 'capital of adulthood' but it was the situation in which this took place that seemed particularly significant for my participants. It was 'being seen' to be able to drink in public 'adult spaces' like pubs that are closed to younger people that seemed to be important. The second theme that has been outlined in this chapter is 'Adulthood is - Independence' and this has been considered in terms of the specific types of autonomy and self-determination that were being referred to by my participants when they used the term 'independence'. The third theme discussed is 'Adulthood is - Domestic Competence'. This theme, along with the 'necessary' consumption of alcohol as a signifier of adult status, also emerged early in the research process. Learning how to mop the kitchen floor is important it seems if one is to obtain the 'capital of adulthood'. As outlined in the conceptual model that I have developed based on this phenomenological analysis, the three themes referred to above were linked to behaviours and skills that contributed to the fourth theme considered in this chapter. This was the 'code of behaviour' that signified adult status. 'Being sensible' seemed to be an integral part of this 'code' and it seemed that consistent adherence to a 'certain way of being' was considered to be important to my participants. These themes in turn led to the final theme that is discussed in this chapter – 'Adulthood is - an Achievement'.

The interpretation I have taken from my analysis as a whole is that maintaining certain, specific behaviours were seen by my participants as key to achieving recognition of their adult status. These are related to the cultural field in which the research was conducted and also the habitus which has been developed by the young women in my study as a result of their past histories and experiences.

In order to illustrate how the ‘subthemes’ that emerged from the analysis were used to generate the ‘superthemes’ I have used the table below. Although the number of subthemes generated was considerable and it would not be possible to include all of them in this table I have grouped together some of the subthemes as ‘primary’ subthemes. Not only did they appear more frequently than other themes but they were given more weight when expressed by the participants in the interviews. It was not only the number of times that my participants referred to the importance of ‘being sensible’ that suggested that they considered this to be important for the ‘code of behaviour’ of adulthood but the way in which it was expressed – as a self-evident fact – that highlighted that this was a key theme.

Table 1.2

Alcohol = Adulthood	Adulthood is – Independence	Adulthood is – Domestic Competence	Adulthood is – a ‘Code of Behaviour’	Adulthood is – an Achievement
Drinking in public spaces like pubs and nightclubs Drinking legally Drinking with peers Drinking away from ‘adult’ scrutiny	Freedom from the scrutiny of authority figures Privacy Freedom to travel Financial independence Making your own choices	Cooking Mopping the kitchen floor Doing laundry Grocery shopping Childcare	Being ‘sensible’ Being ‘mature’ Maintaining mature behaviour consistently Being on time Taking responsibility for yourself	Adulthood as ‘hard won’ Adulthood achieved through difficult experiences

Alcohol = Adulthood

It would seem that drinking is important. When asked about the advantages of adulthood, all of the participants I interviewed talked about drinking alcohol. They appeared to hold it central to their perception of adulthood. It was as if it was on the tip of their tongues as soon as I began the interviews –

I – We were talking about the advantages of being an adult.

'L' – Alcohol. You get to drink it.

I – Yeah?

'L' – Legally, and it's great.

One of my students went so far as to suggest that going to the pub is a prerequisite for being an adult.

I – What's a suitable activity for an adult?

'M' – They can go to pubs.

I – But if they don't go to pubs are they still adults?

'M' – No. Then they're teenagers.

I – You need to go to a pub...?

'M' – To be an adult. Yeah.

Compared to her peers, one young woman I interviewed appeared to have had more experience of drinking and identified/perceived the injustice of strict limits placed on young people at the epilepsy centre in terms of their alcohol consumption. Accurately, she pointed out that if they were university students there would be no such restriction.

'A' - And it's a bit silly to just have just two pints because nearly everyone here is adults. And if you'd gone to uni, we would have been allowed and I think we should have been treated the same way, bit like if it's uni. And we should get to do it every now and again, have a bit of laughter. And we still, if we get a bit sick, we can go to the medical centre. The nurses will look after us.

'A' was the only participant who referred to the mood altering effects of drinking. Unlike the other young women in this study she stated that she had been drunk on several occasions. The final part of the quotation above is highly revealing however. My participants were accustomed to having a team of nurses on call to meet their needs. The socialisation which has resulted from constant access to medical attention is

apparent in this comment and it would seem that 'A' expected 'the nurses' to take responsibility for the ill effects of excessive alcohol consumption. The young women in my study appeared to particularly value entry into pubs and nightclubs, places which hold the key to social acceptance as an adult. Drinking *legally* is the draw, rather than drinking to feel any different. The link between adulthood and drinking alcohol is reiterated by another of my participants, who identified that adulthood had important advantages -

'C' – 'cos you can go out and... do more exciting things than if you were a child. When you're with your parents you do things more like you would do with younger children but when you hit the age of adulthood and 18 you do more adult things, going to the pub, drinking, going to nightclubs, adult things.

'J' also linked adulthood with being able to drink in public spaces.

'I' – Is it important to be an adult?

J – To me it is. And I'm sure it is to others too. You can go more places. Into the pub and that.

A review of motivating factors concerning why young people drink (Kuntsche et al. 2005) revealed that most young people report social motives for drinking that were linked to peer acceptance. The reviewers note that the decision to drink may be made concerning the affective change relating to the direct chemical effects of drinking alcohol or the indirect effects such as peer acceptance (Kuntsche et al. 2005, p. 884). The 'direct chemical effects' of alcohol as a motivating factor behind the decision of my participants to drink was only mentioned by one of my participants. Although peer acceptance was possibly a motivating factor behind the value my participants placed on consuming alcohol, the emphasis they placed on drinking legally in public places suggests a broader interest in social acceptance and recognition from authority figures – including parents and care workers - of their adult status. 'A' used the interview I did with her in part to 'campaign' for improved access to nightclubs – and alcohol - for herself and her peers, perhaps capitalising on my interest and the opportunity she had for some rare undivided attention from me. She stated that they 'needed the experience' of drinking

alcohol. Reflecting on this exchange, I realized that as a key authority figure in the lives of the young people in my care I was indeed conferring adult status when I gave them opportunities for consuming alcohol in public spaces. What was also noteworthy to me was that none of my participants mentioned the lack of availability of alcohol within the residential unit. This was a restriction that they did not challenge.

Adulthood is – Independence

When reviewing the transcripts during the process of analysis, I noted that 'independence' often seemed to be referred to by my participants in relation to being able to travel freely and spend time with peers away from the scrutiny of authority figures. One participant appeared to feel that she had gained independence and adult status because she was allowed to go shopping with a friend at the local mall without supervision. Although this seemed limited from my perspective as she was restricted to a confined area for a set amount of time, when asked if she was treated as an adult 'L' replied that she was -

'L' – Most of the time.

I – Can you give me an example?

'L' – We can go off with another student shopping. We don't have to have staff looking at us every second.

For one participant, connected to the idea of thinking for herself, was the desirability of going out without parents or staff. When asked about the advantages of adulthood she stated that -

'M' – You can make decisions by yourself. Or you can go out by yourself. And you can go to clubs. And go out with your mates.

For another, being able to go to the local shops without scrutiny represented 'independence'.

I – What's independence?

'J' – Well... going to the shops on your own and doing stuff by yourself. That's when you know you're like a proper adult. Without people following you around and everything.

As noted, all of my participants expected to work and gain financial independence in the future. This was a subtheme that emerged from all of the interviews conducted. Asked about the importance of employment, one participant stated that -

'L' – You can't live on benefits for all your life. You've got to take care of yourself. You need to earn your own money.

Another linked financial independence with an obligation towards her parents.

'M' – Because if you live... if you want to get your own place you need to have the money to pay for it. Also, if you have bills and all that.

I – For your needs, you have to get a job?

'M' – Yeah. You need to be able to buy the things you want. Because your parents can't do it for you forever.

It is perhaps unsurprising that the 'markers of adulthood' for my participants should include making autonomous decisions and gaining financial independence, as they would for most young people. What was apparent however was a range of ambitions and expectations concerning what form this own independence would take in the future. While one participant identified going to the local shops on her own as a sign that she had gained independence, others expressed more ambitious aims in terms of the vocations they hoped to pursue and the living situations they seemed to envisage. From my perspective as a care practitioner, I felt that my participants had exchanged the restrictions that would have been placed on them within the family home for those that were enforced by policies and procedures at the epilepsy centre. However, when reviewing the transcripts it seemed that my participants had seen leaving home to come to the centre as a positive experience that had offered them more opportunities for independence. This appeared to be key for gaining adult status. One participant referred to the confidence she felt she had gained and when I asked her to elaborate she stated that -

'L' – ... being here and being more independent and learning all those skills made me know that I can do all those things. I never used to think I could... not even basic things. People did everything for me so I never thought I could do things for myself.

When conducting the analysis of the data and pursuing the 'hermeneutic circle' around endless spirals I was reminded that I needed to listen and draw back from the preconceived ideas I had concerning the level of independence that was available to my participants in the 'here and now' of the epilepsy centre and consider what their experiences meant to the young women in my study.

Adulthood is – Domestic Competence

When asked about adulthood in the initial stages of being interviewed, one of my participants immediately gave a very specific list of household tasks which must be undertaken in order to be gain adult status –

'C' – you've got to cook for yourself. You've got to clean your own bedroom. Got to do chores... cleaning the kitchen. Washing the kitchen floor. Do your own shopping. Do your own washing.

Another was similarly focused on domestic obligations -

I – What does it mean to be an adult?

'J' – Keeping the house tidy and stuff like that.

I – House stuff?

'J' – Yeah. The washing up. Laundry.

One participant appeared to associate responsibility for particular 'zones' within the house with the transition to adulthood.

'C' – ... when you're younger your parents do more and just expect you to tidy your room. And they do all the house chores and you don't do the house chores, but when you're an adult you do the house chores and your bedroom.

'C' clearly felt this was an important point as she returned to it and reiterated -

'C' – you're supposed to look after your bedroom and the house... and not just rely on other people. You can't rely on everybody. You're supposed to do that job. And your room. And not rely on the people in the house with you to do that job. And your room.

In order to prepare the young people we work with at the epilepsy centre for greater independence we teach them the practical domestic tasks they will need to care for their own personal space and a future which will probably involve living in a shared house. What was notable it seemed to me during the analysis of the data was the way in which very specific domestic tasks were outlined rather than a summary concerning the need to maintain general housekeeping standards. These were the specific tasks that the participants in my study had been taught within the residential unit. Griffith (1994), when comparing the lives of young people with learning disabilities with non-disabled peers, states that –

'Most adolescents do not dust and keep their cupboards, drawers and rooms tidy. They do not eat sensibly, go to bed early, do as they are told or behave in an exemplary way towards the other sex' (Griffith, 1994, p.65).

However, within my practice experience, these are often expectations we place on young people with learning disabilities. As revealed by the comments in these interviews it would seem that the emphasis on learning how to carry out domestic tasks within the residential unit has been effective in instilling the importance of these tasks in the perceptions my participants in relation to achieving adult status. As noted in the ethnographic fiction that follows this chapter however, teaching Evie to take an active part in the running of the household was not always straight forward and what was remarkable was the discrepancy between the importance placed on domestic competence by my participants within these interviews and the evidence that I saw within my day to day work with them.

Adulthood is – a ‘Code of Behaviour’

As outlined in the themes explored above, drinking alcohol, gaining independence and carrying out certain routine domestic tasks all contributed towards what I have termed the ‘code of behaviour’ for adulthood. What was apparent was that there were other behaviours related to attitude that my participants seemed to hold central to establishing and maintaining adult status. This section of my findings chapter focuses on three different aspects of this ‘code of behaviour’. One is the need for maintaining good timekeeping in order to be an adult. The next concerns the need for consistency in ‘mature behaviour’, although it was suggested by two of my participants that occasional lapses were acceptable. The third consideration relates to the attitudes required for adulthood and it was signaled – I noted when reviewing the transcripts - by the regularity with which my participants referred to words such as ‘sensible’, ‘mature’ and ‘serious’ when revealing their conceptions of adulthood.

When ‘A’ was asked about how one becomes an adult she placed an emphasis of the need to –

‘Be on time. Every single time. Like if you make a doctor’s appointment. If you’re travelling somewhere. If you’ve got an appointment somewhere. Like, you know, work. If you make an appointment for the first time. Just make sure you’re there’.

Likewise ‘G’ referred initially to good timekeeping when she gave me her list of behaviours needed for adulthood. It involves –

‘Being punctual. Getting a job. Making enough money so you can afford to have your own house. And do things maturely’.

It must be noted that both ‘A’ and ‘G’ faced particular challenges when it came to timekeeping during their time in my care and it seems clear that the efforts of care staff to encourage better time management had made an impression on how they expressed their conception of adulthood. The other participants in my study did not specifically mention having good timekeeping as a necessary behaviour for adults but they seemed

to share a similarly prescriptive understanding of how adult status would be maintained. 'L' and 'G' both referred to the need for consistency but allowed for occasional lapses. I asked 'L' -

I – what are the disadvantages of being an adult?

'L' – you have to be really, really responsible with things... very grown up with some things. You have to take things seriously and not muck around too much.

I – so, can we act immature and still be adults?

'L' - yeah, if you're in that kind of mood you can. You're allowed to have a laugh but when it comes to the serious stuff... you have to behave mature.

'G' was asked –

I – what's the difference between an adult and a child?

'G' – a child has more anti-social behaviour.

I – what's anti-social behaviour? Give me an example.

'G' – silly behaviour. Rude comments. Showing off.

I – do adults do that sometimes?

'G' – if they're drunk.

I – so the line between adult behaviour is sobriety? Whether you're sober or not?

'G' – (laughs) you know what I mean. Occasionally. They might misbehave. Everyone does once in a while.

This was said in jest but generally the serious nature of adulthood was emphasised throughout the interviews. It is not only the activities they undertake – having a job, paying bills, caring for a house – that define people as adults. It is also the way they behave. 'L' commented on the relative levels of maturity amongst her peers -

'L' – Umm. Some just act a bit more mature than others. They don't like have behaviour problems. Adults shouldn't have behaviour problems anyway.

It is sometimes difficult to identify cause and effect when working with our student population within residential services at the epilepsy centre. Many of our students have significant difficulties with timekeeping. This can in part be explained by the neurological impact of epilepsy on memory and other executive functions. It is difficult to ascertain if always having a carer available to organise and remind you about what you need to do before getting to college each day acts to hinder the development of independence in this respect.

Adulthood does of course involve following of code of behaviour. We all meet certain expectations in the way we conduct ourselves as adults. What my students identified when they set out their code of behaviour was something which seemed very conservative. It was also defined by the views of others. An advantage of being an adult – according to 'G' – is that 'people might view you as a sensible person.' She also mentioned that 'you're trusted. You're trusted to do things correctly.'

Naturally, I asked about this notion of 'doing things correctly' and as it was with many other questions in the same vein, I received a vague and slightly puzzled response. 'G' seemed to suggest in her tone of voice when I pursued this line of questioning that it should be obvious. Some things are self-evident it seems. Did I not understand the proper way an adult should conduct themselves? One of the aspects of the interview process my participants sometimes seemed to find confusing was my sudden ignorance on a great number of subjects.

Adulthood is – an Achievement

Adulthood is not a given. It has to be earned. My students conveyed the sense that they have worked hard to reach the status of adulthood and the privileges this brings. I asked one participant about her education -

I – have you had the education you wanted?

'C' – yeah. It's not easy 'cos of the seizures and I got bullied and that but now I can say I've done it and I've... learned. Grown up.

One of my students stated that she felt she had achieved adulthood sooner than her sibling due to her disability and the additional challenges it had created in her life –

'L' – I've had to grow up more quickly than my sister. There hasn't been as much time for mucking about. Having fun. I've had to take it seriously. Because of the epilepsy I had to make up for the time when I couldn't learn. But I'm proud of where I've got to. Now I am.

Adulthood as an achievement was a theme that emerged more slowly than the others during the 'data production' phase of the research. It was only when I delved further into the thoughts and ideas of my participants that I started to get this sense that adulthood was something that was hard won. Initially, two of my participants presented adulthood as a naturally occurring phenomenon which would happen at a particular age. I asked 'G' –

I – when does a person become an adult?

'G' – when they're twenty-one. Or when they're eighteen.

I – what happens at eighteen?

'G' – You're more mature. You make the right choices. The right decisions.

Likewise, 'C' gave a particular age for when adulthood will 'occur'. I asked her –

I – what makes a person an adult?

'C' - when you hit the age 18.

I - what happens at 18?

'C' – you learn how to behave, you can drive, you can drink, you can vote.

When questioned further however, my participants revealed that they thought of adulthood as a state that they had 'achieved' rather than a naturally occurring phenomenon. Five of my participants appeared to feel that they had achieved adult status but one – 'A' – felt that she had not because certain activities she associated with adulthood were not available to her as readily as her non-disabled peers. I asked her to elaborate –

I – how do you feel about that?

'A' – peed off really. 'Cos I'm not an adult kind of person. I got friends who are doing adult kinds of things. Going out, having a party, drinking.

'G' contrasted how she was treated as an adult within the residential environment with how her mother did not always seem to recognize her adult status. She felt that she had 'grown up' but that her mother had failed to notice this. It seemed that adult status was available to her in some situations but not others. 'M' identified her epilepsy as having a negative impact on how her parents viewed her in relation to establishing and maintaining adult status.

'M' – I think they... umm... like our parents for example... they still class us as kids. They don't treat us like an adult... they make our decisions for us.

I – why do you think this is?

'M' – probably because we've got epilepsy. They think they have to help us more than they do. I know they care and everything and that's why they can be... like that.

This final point leads to the next section of this chapter, which is consideration of the perceptions of epilepsy revealed by my participants within the interviews. This topic could have been the basis of further investigation and would in its own right make for interesting and fruitful research. It is one of several themes and considerations that I have identified within the concluding comments as an area of further work that could come from the research outlined in this thesis.

Perceptions of Epilepsy

Epilepsy means many things to the participants in my study it would seem. It is both something ordinary and something difficult. It is something that has been conceptualized by some as making them stronger as people. It is something that has made them vulnerable, particularly to bullying. It would appear that it can mean several different things within an apparently homogenous group and can take on different meanings for individuals depending on context. It does not appear to hold a static meaning. Like Ninjof (1998), I concluded that the experience of having epilepsy is heterogeneous. I asked 'J' about her epilepsy -

'J' – I don't think about it. It doesn't affect me much I don't think.

'J' actually gave the opinion that it was her learning disability that provided more of a hindrance, this being something that was ever present and unlikely to ever go away. Another participant said –

'G' - it has affected the mature part of my brain. It made me, I mean I used to have behavior problems and that's something I regret a lot. What I did to my family. I used to be a proper cow.

G particularly identified the 'comorbid' impact of epilepsy on her learning and behaviour as being difficult to cope with –

I – what was difficult about epilepsy?

'G' – not being able to understand anything, learn anything... make friends. Not being able to get on with my family so well. Not being able to do as I was told the first time.

When asked about her epilepsy, 'C' expressed mixed feelings –

'C' – I do get sad or angry sometimes but other times I just get on with it. Everyone here is in the same boat, we've all got something and some people have got, like, worse than me.

One participant seemed able to view her epilepsy differently due to improved seizure control –

L -Well. It used to be all there really was in my life because I used to have lots of seizures but now it's more under control... I don't really think about it so much. I take my meds. That's it really. It's part of the routine, I get dressed, I take my meds. It's like brushing your teeth or something.

'L' stated that epilepsy –

'L' - ... doesn't get in the way anymore. It has probably made me more understanding about other people and the fact that they might have problems too.

All of the participants in this study reported being bullied as a result of their epilepsy within mainstream education settings and most referred to bullying as a first response when I asked them about school experiences. They also referred to the positive impact of being in a setting where 'everyone is in the boat'. It would seem that spending time in an educational setting with other young people with epilepsy was viewed by my participants as a positive experience. I asked 'G' about growing up with epilepsy -

I – what has this experience meant to you?

'G' – ruined my life to begin with but it helped me to be a stronger person as well.

Attitudes and the ability to cope with epilepsy may have been different for my participants had they attended a mainstream college and had fewer peers with disabilities. This is impossible to measure however and conjecture is all that is possible. All that can be said with certainty is that it appeared to be the perception of my participants that they were better off in a special educational environment. In the words of one, she was 'glad to have been given a shot.'

For my participants, it seems epilepsy is more varied as an experience than most of the literature – as outlined in the review in the previous chapter - would suggest. This is consistent with a 2005 study which found discordance in the impression one might legitimately gain from the literature and the lived experience of those with disabilities. Disability was described as a '... multifaceted, complex experience that is integrated into the lives of persons with disabilities' (Lutz & Bowers, 2005). They suggested that

there were three disability-related factors that influenced the way participants in their study integrated disability into their lives – the fundamental effects of the disabling condition, others' perceptions of disability and the need for and use of resources.

Taking this model and applying it to the participants in my study suggests that their coping mechanisms could be related to the availability of resources – including my own presence as a carer and provider of emotional support and practical assistance – the acceptance they found from peers with the same disability and the fact that for each of my participants seizure control was such that epilepsy was not preventing them from doing many of the activities they enjoyed. The fundamental effects of the disabling condition were not unmanageable on a day to day basis.

This analysis of the data has produced particular themes relating to the perception my participants have concerning adulthood and how adult status can be gained. These themes have been reflected in the following chapter in the ethnographic fiction that also elaborates further on my relationship with my participants and the professional and personal context for this study.

Chapter Five - Findings Part II – Evie/I

Prologue

No one meant her harm, and yet she hurts.

This is where I am beginning.

That afternoon, the garden was like an archaeological dig.

This is how I picture it.

There is a way to tell her story and I will find it.

This is where I get stuck. This is where I almost turn back.

There are three beginnings to this story.

There are three stories I want to tell you about Evie.

Part I - lifeworld

In the first story, we are living in the lifeworld. This is how I think of it. It is the day-to-day stuff. It is the life we are living when the washing machine breaks down, the cat is sick on the carpet, the milk tastes tainted. It is the realisation that the bottle of stain remover in the cupboard under the sink is empty. It is the bleak news on the television when you

are drinking your black coffee in the morning. It is losing your keys when you are running late. It is knowing when you are leaving a message for the washing machine repair place that they will fail to return your call.

It is something we must keep in perspective; shape into a more reasonable version of events. It is not the end of the world.

Also there in the lifeworld is a friend who sends good news and makes bad jokes. There's something on the radio that makes you laugh out loud. It is that mix of everything, and all at the same time. Sad, crazy, clever, depressed, frustrated, happy, witty and full of joie de vivre. And all before lunch time.

I met Evie for the first time in the lifeworld - in the ordinary, everyday world of my working life. She was nineteen years old.

The epilepsy centre where I work is the modern incarnation of an 'epileptic colony' that was established more than a hundred years ago and still specialises in epilepsy. It has a sprawling campus spread over sixty acres, with buildings of various ages and with different purposes. It is situated on the outskirts of a village, a community apart.

Evie has epilepsy and – according to her notes – she also has a learning disability, emotional and behavioural problems and a rather lengthy history which I had already read, thought about and discussed with a number of colleagues before she'd taken one step inside the door.

I knew intimate details of her life and that of her family.

She knew little, if anything at all, about me.

Evie's file was particularly heavy, weighed down with measurements and descriptions, with medical opinions, reports and details. The smiling photo inside the cover was a school-girl, taken a few years ago I guessed.

I remember dark-smudged eyes, gluey lashes, high-heeled boots. There was a hint of antagonism about Evie which was not focused on anyone or anything, perhaps a deliberate slowness to her movement, as if measuring the situation. Although I may have imagined this of course.

Retrospectively, I even wondered if I'd made it up.

It was September 2005 when Evie moved into the residential care unit where I am the manager. I've been doing this job for several years now. I have learned that there are certain patterns. I can make predictions.

For example, I know there will usually be a honeymoon period. This is when our new students arrive and we might even begin to doubt the mention of behavioural and emotional problems in their notes. This time of polite manners and smiling compliance usually lasts six to eight weeks. Evie made it to seven weeks, about average.

This was when we had the first of what we call 'incidents', known locally as 'kicking off'.

Evie had a confrontation with one of the other students on the house, exact cause unknown. She fled from the back door, punctuating her distress with a loud slamming of the door, consumed by rage and indignation. She did however wait until she could be sure I was following before she picked her direction for absconding.

Evie allowed me to walk her back to the house after she'd had time to recover, after the name-calling and the venting. 'I suppose,' she said – with venom – 'you're going to write an incident report.'

Indeed, I would be writing an incident report. It would be available for all the other professionals to see and perhaps discuss at one of our multidisciplinary meetings. Evie had learnt the ropes very quickly. She knew how we operated.

Evie has a moderate learning disability. She is considerably more able than some of our students, those who have more severe cognitive impairments.

People sometimes point this out to Evie. She is lucky.

She should – somehow they suggest – be grateful.

I have never said this to Evie.

This does not matter even slightly when she makes the decision that she is going to take it out on me. She tells me - ‘Just because I am more *able* doesn’t mean I hurt any *less*.’

I know, I know, I know, I tell her.

The severity of the epilepsy, the seizure control and where on the scale the learning disability lies can mean nothing compared to the emotional experience of what it feels like to be *that* person with *that* condition. And the labels that come with it.

But I don’t know. And, naturally enough, Evie is very quick to point this out. ‘You don’t have epilepsy. You don’t have a learning disability. You’ve never been sent to see a *shrink* because of your *emotional problems*. You don’t know what it’s like.’

What I do know is that when Evie is upset I want her to stop being upset. I know that. What I don’t know is how to comfort a person who is so distressed about something that cannot be changed.

Every so often, I give in to the pleas, the demands, the begging and the bare-faced emotional blackmail. I agree to take my students to a nightclub.

Saturday nights are occasionally sacrificed to give them what is a normal night out for young women of their age.

We arrive by Sunshine Variety Club minibus, decorated in bright colours with cartoon drawings. It is not normal.

None of the other clubbers have specialist surveillance.

The other clubbers have probably not had an obligatory reminder – as I must give my students - about consuming no more than two units of alcohol. This is how much my students are allowed to drink, according to policy. Although the concept of a unit of alcohol can be difficult to explain. I ask them to only have two drinks and never mind the units.

I'll settle in the corner by the bar with a diet coke and a book to read, glancing up every so often to monitor the situation. I will, of course, attract some odd looks. Every so often someone will want to know what I am doing, even offer to buy me a drink and I will have to deflect unwanted attention discretely.

My students will fumble in their wallets for their ID at the bar, brandishing it before being asked, buying the sickly sweet concoctions favoured by inexperienced drinkers. They will also look over in my direction every so often, needing to know where I am too.

I'm always surprised they accept the limitations on alcohol so readily; astonished it is not challenged more often.

The official line is that there is a risk alcohol will interfere with the epilepsy medication. The unofficial line is that it is difficult to regulate drinking and it is easier to avoid problems in the first place.

Sometimes, I will have a student who pushes the boundaries, making curiously blatant attempts to sneak more booze, as if they want me to know they are flouting the regulations. Most don't however. They conform to the rules about alcohol in a way that makes me realise how different they are from the other young people in a nightclub on a Saturday night.

Evie usually sips a WKD Blue for an hour then switches to diet coke, although she will always claim to have a hangover in the morning, as a badge of honour.

Like many of my students, it seems that Evie has never been expected to undertake any kind of domestic task. We are starting from scratch.

This is a *Hoover*. Here is a *toilet brush*. This thing here is a *washing machine*.

You will need to put your *clothes* into the *washing machine* if you want them to be *clean*.

We set up a rota delegating tasks to each of the students, explaining that this is how things get done in any shared house. But the trouble with the rota is that our students learn the rota. They learn how to follow a routine. They do not learn how to clean a house. If they normally clean the bathroom on a Wednesday, they soon develop an inability to clean it on any other day. Even if it is dirty. We have yet to solve this problem.

Evie discards crisp packets and diet coke cans, leaves coffee cups and crumby plates all over her room. She tries her best to avoid her share of the domestic tasks, keeping a low profile when it's her turn to empty the dishwasher, pretending she has conscientiously cleaned her room despite evidence to the contrary. It is another problem we have yet to solve.

Meanwhile, the pile of clothes waiting to be ironed grows higher still in my spare room. There might well be washing up in the sink from the night before. There are usually coffee cups on my desk. Solutions to my own domestic ineptitude are also elusive.

Evie has a younger brother, Daniel. I've met him and he seems like a nice kid. According to Evie, he is not a nice kid. He is a pain. He thinks he knows it all. He thinks

he can tell Evie what to do. This is something her mother allows, even though he is five years younger than Evie. She burns with indignation when she reports this to me.

The dynamics of the younger-older sibling relationship have been thrown out of kilter by Evie's epilepsy. Daniel has been asked on occasion to stay with Evie in case she has a seizure. He takes this to mean he can tell her what to do. This is Evie's interpretation of the situation. Whether or not this is true or is something she simply feels to be true, it is one of the battlegrounds where Evie and her mother regularly come into conflict.

Evie is sharing a house with six other young women who also have disabilities. It is fair to say that she is not very good at sharing. She has had little practice at it. Her position in the family as the 'disabled child' is one which has guaranteed ample attention and dispensations. Her mother admits that they have treated Evie differently due to her epilepsy. It is difficult to adjust when this is taken away, when you are one of several young people with this condition. But Evie soon learns how to compete for her share of attention. She is soon very good at it.

We care, we really do.

We all want what is best for her. Evie knows this, but sometimes she doesn't feel it. She gets angry at us, accusing and saying things that we know that she does not mean. We want to protect her. We record seizures and adjust medication. We offer therapy. We are endlessly creative with our efforts. We search for answers, knowing how elusive they are, how futile the attempt is likely to be. By the time two or more medications have been tried and failed to achieve seizure control the odds are stacked against us.

We are the people brought together by our professional relationship with Evie and her family. It is a group which includes doctors, nurses, therapists, social workers and

tutors. Crowded into rooms for review meetings, we will debate and record. We will put forward our theories and scan our professional experience for answers.

But we also go home. We put on our coats and assume other identities as family members, parents, partners, friends, people going about our normal, day to day lives.

This has not gone unnoticed.

Evie will sometimes become raise the question of our relationship to her in an accusatory tone. We are 'paid to put up with her'. We only *care* for her because that's our *job*. She tests the limits of our tolerance.

Evie and I fall out with a regularity that gets tiring. It can be very draining. She will pick an argument over a perceived slight, and the door slamming, insults and sulks will go on for days. The sight of me will inspire strong emotions, emphatic sighs and tortured expressions. She will tell anyone within listening distance about how terrible I am. Mostly I know that it is my position she is reacting against, my role as a kind of parent figure. I don't take it personally. I try not to at least.

Like many of the young people I work with, Evie has memory problems related to her epilepsy. She can be very, very angry with me, knowing she is angry with me, but unable to recall quite why.

I counter these situations with complete calm and a failure to react.

I wait for Evie to want to talk to me once more. I have learnt it is best to wait.

I also go off shift. This is something that her family don't get to do when Evie is at home. I walk the dog, meet friends for a meal. I return to work the next day and resume as if nothing has happened.

It is gradual but after a while Evie and I stop having these one-sided arguments. The pace slows and then the frequency drops away to nothing. The incident reports stop accumulating.

We can even share a joke about how she gave me a hard time. She stops fighting so much with her mother. She is getting on better with her brother. She starts to adopt a 'big sister' role and proudly shares stories about how good Daniel is at football.

Evie tells me she thinks that she is growing up – and that her mother has really improved since she had moved away from home. The distance created by a residential placement will often help these intense relationships.

In the months before she left my care, I started to interview Evie. I explained that I was going to be doing some research involving young women like her. I'd hardly finished what I was telling her about the study when she agreed to take part. My one time adversary who would stop speaking to me for days at a time was keen to talk.

Part II – The Garden

The garden was like an archaeological dig, she told me, laughing as she described it.

Helen had broken into a sweat and so far she had only uncovered a small patch of unpromising ground. She'd paused to cast doubt on the fertility of the earth, which had yet to offer anything hopeful from all of this labour. After an hour of digging it had offered broken bottles, parts of a rusty barbeque and pieces of an unidentifiable machine. She'd found fragments of fabric, remnants of a plastic doll with missing limbs. There could have been human remains buried among the debris for all she knew.

I'm actually the one who pictured the unearthing of a body. Helen never mentioned it. I am the one with the macabre imagination.

Helen is Evie's mother. I met her the day that Evie moved in. I took down her work and home numbers, contacts in case of an emergency. We exchanged courteous smiles. I tried to inspire confidence. She tried to look confident, perhaps more certain than she really was about her decision to place her daughter in residential care.

Several months later, Helen and I had gotten to know each other and established a pattern of having coffee together when she dropped Evie back after a weekend visit home. This was how we came to be sitting in the kitchen with Helen telling me about Evie's experience of primary school.

Helen was at work when she took a phone call from the school. She was asked to retrieve her daughter. The other children were upset because Evie had been responsible for ruining the little garden where they were growing sunflowers and runner beans. There had been some kind of confrontation and two of the children were crying inconsolably after being hit. The classroom teacher, who had a bruised shin from trying to intervene, was likewise not happy.

When Helen had arrived at the school, she found Evie in a corner of the corridor - red-faced, fists clenched, with an anger that seemed beyond her tiny dimensions. It was the point, Helen says, when she knew she wasn't making things up. Something wasn't right.

This moment of realisation is not uncommon. I have heard similar stories from parents like Helen before. They often know before the doctors, sometimes despite what doctors have told them.

Helen told me about how they had encountered the behavioural problems very early on. Evie was a late developer in almost every respect - apart from her temper.

That was where she excelled. Evie's tantrums were beyond compare.

I must admit, they are very impressive.

The day after she was asked to collect her daughter from school, Helen stayed home from work. She was determined that Evie would not miss out on educational experiences. If gardening was such an important part of the curriculum then Helen would create this for her daughter. She would labour, dig and sow and create a garden from the unpromising patch of ground behind their rented house. It was a show of her resolve.

I am embellishing here you must realise. Helen only told me she had created a garden. Not about what it meant.

The garden, Helen then told me, had gone to ruin soon enough when hospital appointments and visits to psychologists began to occupy their time more and more. This was after Evie had finally been diagnosed with epilepsy. It was when they were learning that the behavioural problems and developmental delay were likely to be linked to the epilepsy. This was when it was discovered that the brief, staring spells that Evie had weren't merely daydreaming, and that their lives were about to be very different.

Evie was six when she experienced the first generalised tonic-clonic seizure. Like many parents seeing this for the first time, Helen thought her daughter was dying. By the time they made it to A & E, she'd had a further seizure. Another soon followed. Medication was given and when this failed to take effect more was administered. When she counted five doctors in the room, Helen knew it wasn't going well.

The seizures did stop eventually and Evie, drugged and small and helpless, began to re-emerge, started to look more like herself once more. They were sent home from hospital two weeks later with prescriptions to be filled and a diagnosis of epilepsy.

It was at this point in time when Helen and her husband began their unwanted medical education. They would soon know a lot about epilepsy, growing fluent in a language they had no desire to speak.

Helen finished her coffee and told me that she hated looking out from the kitchen window at the garden in the months that followed, at the plants gone to seed, the healthy weeds, symptoms of a kind of failure – (*my interpretation*).

What I also know about Helen is that she has suffered from depression and that medication has not been helpful. The doctor taking the history I had read also recorded that the parents did not find their attempts at therapy useful. These intimate details are kept on record. Marital difficulties are common among parents with disabled children. So common that Helen didn't need to tell me. I could have guessed.

Some of the things Helen has told me about her daughter and her history contradict what Evie herself has told me. There are also details Evie includes in her story which appear fanciful. She told me a dramatic story about a near death experience when she was eleven, about being saved by angels. She told me about visits to a 'shrink', who was really a psychologist. Evie had upgraded her to a psychiatrist. I did not correct her. It is her history, her story. She can tell it how she likes.

While I was Evie's carer, Helen and I formed a kind of alliance.

At times, Evie would fly into a rage and threaten to call her mother, reporting her ill treatment at my hands I imagine. Not if I call her first, I would say. Although I never did. And nor did Evie.

Helen's wrongdoings were reported back to me and we came to share a sort of understanding, both knowing how difficult it can be to be on the receiving end of Evie's temper.

I cannot separate Evie from Helen, and what she has told me about the past.

I cannot separate Evie from the files I have already read.

These things were with me when I started to research Evie's perception of the world. I already had my perception of Evie.

Part III – The Summer Years

It is a secret I keep even from myself; an inevitable mystery. How much of Evie am I observing and reporting, and how much am I composing?

In the final story, I am a researcher – a particular kind of writer - worrying at the problems late at night.

Locked in my study, in the company of cats and books and thoughts, I'm not sure I trust myself. Writers - I have heard it said - are like cannibals. They feed on whomever and whatever is around them, starting with their families of course.

I think about the phrase 'in loco parentis', and wonder if I'm covered morally by perhaps acting on a natural compulsion in taking my material from those around me. I've also heard it said that writers are like alcoholics. They write because they cannot help themselves. They cannot choose to do anything else. I reflect on this and wonder if this theory was devised by someone who needed an excuse for both habits.

I call it my study but really it is a room between two other rooms, housing the boiler and an eclectic library, a skip-rescued gate-leg table for a desk. There are pictures leaning against the walls, still waiting for hanging four years on from when I moved into the house. There is a houseplant on the desk, struggling with my lack of nurturing – a poor indictment for a care worker. It is an incomplete space, a potential place, a room for possibilities, some of them helpful, some of them not so useful. This is where I sit to write and try to make meaning.

I think myself back to her age. I don't remember a preoccupation with the meaning of adulthood and I think I was like Evie in that I was anxious to pretend that my own 'coming of age' had occurred organically by the age of 18 and I was by then fully formed and mature and it could be taken for granted that I was an adult. Perhaps I imagined that this had taken place spontaneously during the flight from my small-town origins to the city where I enrolled in university – Wellington - and hastily set about acquiring the 'capital' I would need in a very different 'cultural field' (Bourdieu, 1998). I wouldn't have referenced Bourdieu in those days – with my head full of Katherine Mansfield and writing ambitions – but when I start to unravel the mysteries of the past, to consider my own habitus and how I came to interpret the things that Evie told me, Bourdieu begins to make sense, to lend meaning.

It was not merely the 'capital of adulthood' that I was anxious to acquire when I was Evie's age. I wanted to be a writer and what I valued was 'artistic capital'. It was true that I wanted to be perceived by others to be mature and worldly and I was particularly concerned that any lack of sophistication due to my unfortunate origins in a small town should be disguised. Cities were alien to me and Wellington was particularly cosmopolitan. I struggled to learn how to fit into this particular cultural field, to learn the 'rules of the game'. I drank cappuccinos for months, not because I liked them but because I knew what they and could confidently order them from a cafe menu. Eventually however I did start to acquire the kind of artistic capital that I so desperately craved when I gained a prized place on a creative writing course and began publishing poetry in literary magazines. This was followed by the realisation that this kind of capital is easily taken away. Harsh words from a critic remain etched on my sensitive memory.

Evie and I are not so dissimilar. I had always thought we were 'worlds apart' in more ways than one as I made my own transition into adulthood on the other side of the world as a university undergraduate. I compared the level of freedom I had and also the responsibilities that came with it. I was not subject to scrutiny in the same way as Evie. I was free to choose my own direction to a far greater extent, to make my own way in the world, provided I could create the financial capital necessary to facilitate this.

Evie and I both behaved in certain ways to achieve certain kinds of capital. We dressed, acted, spoke and presented ourselves in certain ways in order to be perceived by others as we would wish. We were not so different after all.

I started interviewing Evie almost three years after we first met.

I thought – at the time – I knew her well. I made predictions on a certain level, perhaps even subconsciously.

The first thing that took me by surprise was how different it was to be talking to Evie with a Dictaphone running. She hid her face behind her hand to begin with, caught by a sudden shyness I didn't expect to see.

After a while she lost any wariness and started to talk, revelling in having that thing she had competed with her peers so fiercely for over the years, my undivided attention.

There were some things I hadn't considered asking Evie, until I started to think more like a researcher.

During the years that I had been Evie's carer we had talked at length. We'd talked about her family, her friends, boyfriends, her ideas about right and wrong, what she thought about all kinds of things. We traversed the moral territory of human relationships. We discussed popular culture. We'd talked about the trivial and we talked about things that mattered. I was surprised to find so many things that I didn't know about her.

Despite it all, I found out that Evie wanted to please.

She wanted to please her family, and in a way she wanted to please me. Adulthood, if you ask Evie, is about not being a burden to others. It is doing things for yourself. She even mentioned the washing up she was always so keen to avoid, presenting an image of domestic dedication I had seldom seen in real life.

Adulthood is drinking – legally - and using your ID in pubs. It is WKD Blue and Bacardi Breezers. It is fitting in. It is being a good daughter.

Evie's life is not all about epilepsy. She is ambivalent when you ask her how it has affected her. Sometimes she says it has and sometimes she doesn't feel that way.

I read good advice and learn from the mistakes of others.

I read conflicting advice and make the same mistakes as everyone else.

I lose references and fail to return my library books on time.

Every year, I look forward to the summer holidays.

This is when I will have the time and the thinking space to try to make sense of it all. And somehow anticipating the luxury of time makes the weeks seem like years. I plan ahead ambitiously for the 'summer years'. Bourdieu refers to it as 'skhole' – the kind of 'free time' needed for 'scholarly contemplation' (Webb et al. 2002). I travel to the library in preparation and carry home weighty volumes to stack next to my desk, hopeful they will give me some insight, offer help with the 'sense-making'.

The summer after Evie left my care I listened to the recordings I had made of our interviews, listened to them over and over again. I thought about questions I could have asked her and maybe should have. I grew tired of the sound of my voice, listening tentatively for patterns to emerge. In the recording we are often laughing, sharing jokes, an easy rapport. Something gets lost in the process. Occasionally it feels as if I am eavesdropping on a private conversation that doesn't directly involve me.

Sometimes I think about how this space will be occupied when Evie has gone. Who will replace her? What happens next?

In the end of course, there are more than three stories that I could tell you about Evie. I have written and re-written so many versions of Evie, so many versions of myself in the story of me and Evie. In the end, it is late and I need to switch off the light. I will need to leave it for another time.

Epilogue - Evie in the Real World

It is the mundane detail I am drawn, the commonplace stuff.

Everyday. What is normal.

Catching a bus.

Going to work.

Using an ATM machine.

Shopping at Primark.

These things are hard-won for someone like Evie. It takes longer to learn the things that others may take for granted. Her experience of catching a bus will be quite unlike what it would be for you or me. She will hand over her fare and take her seat with a different kind of feeling.

I can see Evie developing a taste for alcopops and drinking too many occasionally on the weekends, arguing with her mother over nothing, creating dramas. Slamming doors.

She will get to play out her 'teenage rebellion' a little later than most, a few years on. This is what happens when you slow everything down so much with all that care and protection. It takes longer to get there.

Evie now works – in my imagined version of events – in a supermarket.

She will need help to learn how it all operates, the systems, where everything goes, how it works. It will be harder for her. She will need help if she has a seizure, and an employer who is prepared to accept the risks. She'll need to learn to manage her temper. I predict this will be a particular struggle.

Evie has a boyfriend in this world, someone she met at work.

They meet to go to the cinema, have a drink at the pub near her flat. He knows about her epilepsy and he's ok with it. He has met Evie's mum and they get on, some times better than Evie herself gets on with her mum. He comes over quite often. He starts to be part of the family. It is early days yet but sometime in the future Evie and her boyfriend might get a flat together. Somewhere close to work, not too far from where her family live.

What I don't want is for anyone to ruin this picture. I don't want phone calls from care managers, or from supported living providers who are reporting a 'few problems' with Evie.

Sometimes things will go wrong for young people like Evie.

Living arrangements - set up by a social worker with the help of the hopeful family - won't work out. The young person won't cope with greater independence, either emotionally or practically and in most cases both aspects will be a problem. The support they were supposed to get might not come through. The staff who were meant to go in to help might turn out to be unreliable. It may start well, with high hopes, but go downhill from there, the disappointment worsened by the initial optimism everyone felt.

I want to provide work references. I don't want to answer questions about how to manage Evie's behaviour and her low moods or provide advice about what to do when she's being unreasonable.

I don't always know what happens to my students once they leave my care. Sometimes there is a strong attachment and I will continue to hear from them, occasionally for years

to come. I will receive regular communication in some cases, attempts to continue the 'carer and the cared for' relationship. This always makes me feel a bit sad.

Some of my former students will call for telephone consultation, wanting help with relationships, expressing frustration with their new support staff, seemingly oblivious to the tensions that once ran through our own relationships when we were locked in battles over boundaries. They don't seem to understand that they have been replaced by other young people, who are also vying for my attention. I will need to make excuses, remind them I'm busy, that I have things to do. I will have to tell them I have paperwork to complete.

I have done my job well when I never hear from them again. It makes me feel that I have helped them to gain the independence they need to go on with their lives and forget about me.

Of course, I will talk about Evie sometimes, with affection. When I come across a situation that reminds me of her - something she did or said - I'll recall what she was like. I might even feel slightly nostalgic for the way she gave me so much grief. I'll refer to Evie's 'healthy disrespect for authority' with a touch of sentimentality. She made quite an impression. I will also know that there was another side to her.

The people we meet and engage with change our perceptions of the world in subtle or more obvious ways. I think differently about certain things after the study I did with Evie and her peers. I feel more inclined to question why, less likely to take what I see on face value. I learnt more about Evie's perceptions, and more about my own

Chapter Six – Discussion - Bourdieu & the Capital of Adulthood

Making Sense

On one point in particular, Pierre Bourdieu was very clear. It concerns the need to tackle the ‘... continued divorce of theory from research’ (Bourdieu & Wacquant, 1992, p. 3). As it is with method, ‘... theory properly conceived should not be severed from the research work that nourishes it and which it continually guides and structures’ (Bourdieu & Wacquant, 1992, p. 30). Bourdieu’s insistence on the central focus of theory in research is not as an abstract concept but as a way of addressing real issues. He decried what he describes as ‘intellectual bias’, the ‘... tendency for some agents (in fields such as the arts and academe) to ‘abstract’ practices and to see them as ideas to be contemplated rather than problems to be solved’ (Webb et al. 2002, pp. 50 & 51).

Bourdieu saw his work as a way of ‘changing things’ (Webb et al. 2002). It has been suggested that ‘Bourdieu’s theories are produced by, and oriented towards, a task – for instance, making sense of why students from different class positions have different success rates at school’ (Webb et al. 2002, p. 47). It is this practical focus that has indeed, in relation to this study, made Bourdieu ‘good to think with’ (Jenkins, 2002). In his account of Bourdieu’s work the critic Richard Jenkins also notes that Bourdieu has a tendency to use unnecessarily ‘long-winded, obscure and complex’ language and he refers to what Bourdieu himself described as ‘a permanent struggle against ordinary language’ (Jenkins, 2002, p. 9). His purpose has perhaps been thwarted at times by his inability to express his ideas in a manner that lends itself to practical application. Wacquant refers to how Bourdieu’s work ‘is not free of contradictions, gaps, tensions, puzzlements, and unresolved questions (Bourdieu & Wacquant, 1992, p. xiii). In one instance Bourdieu passes the responsibility for misinterpretation of his work on his readers -

'I blame most of my readers for having considered as theoretical treatises... works that, like gymnastics handbooks, were intended for exercise, or even better, for being put into practice' (Bourdieu in Calhoun et al. 1993, p. 271).

It has been suggested that Bourdieu's approach is 'complicated' but –

'... in defense he argues that social reality itself and social science (anthropology, sociology, education and history) must inevitably create the concepts and methods to reflect and understand such a reality (Mahar et al. 1990 p. 4)

Despite difficulties which may arise from the interpretation of Bourdieu's work, his framework has however provided a useful way to work with and theorize the findings from my study. This chapter includes a synthesis of the findings from my research using three of Bourdieu's key concepts – habitus, cultural field and species of capital. The theoretical framework provided by his work allows insight into the interpretation which may be taken from the phenomenological reading of the data as outlined in the previous chapter. The 'taken for granted' nature of so many of the perceptions and assumptions my participants seemed to carry with them fits particularly well with Bourdieu's concept of habitus. Habitus has been defined by Bourdieu as '... the strategy generating principle enabling agents to cope with unforeseen and ever-changing situations... a system of lasting and transposable dispositions which, integrating past experiences, functions at every moment as a matrix of perceptions, appreciations and actions and makes possible the achievement of infinitely diversified tasks' (Bourdieu, 1977, quoted in Bourdieu & Wacquant, 1992, p. 18). For my participants, the development of habitus has taken place in the context of having a medical condition with particular characteristics.

The cultural field within which this research took place is a specific social and physical space that shapes the way in which agents relate to each other. The participants in my study were living within a residential campus which is a kind of community within a community – a collection of student houses, staff houses, educational and other facilities set on the outskirts of a rural village. As noted in the introduction to this thesis, it is an institution with more than a hundred years of history, evolving from an 'epileptic

colony' to a hospital school and it now takes its current form as a residential special school and college with medical facilities, therapy, assessment and rehabilitation services. This cultural field has a distinctive language denoting common understandings and this is explored within this chapter as well as specific characteristics of a field operating within a markedly medical paradigm. The distinctive features of the field which may be influential in terms of the habitus that develops as a result of an agent's situation and position within the field are explored.

It would seem that my participants attached particular meaning to the capital which comes from 'markers of adulthood' and that this was related to but distinct from other types of capital. As noted, I have termed this the 'capital of adulthood' and have considered this in relation to how it is gained – through acquiring and displaying certain behaviours - and what benefits the agents (participants in my study) believe it confers, particularly in relation to social status. I have explored the capital of adulthood as a distinct type of capital that is supported by the acquisition of certain other types of capital but remains perhaps the most important – in the eyes of my participants it seems - in that it brings benefits, status and recognition.

Bourdieu also recognized the need to examine one's own habitus through a reflective stance when interpreting and suggesting possible readings of research findings and situations (Bourdieu & Wacquant, 1992). In this chapter I have therefore also briefly detailed the cultural influences which I have brought to bear on my interpretation by comparing my own transition to adulthood with that of my participants and considering the influence this could have potentially had on how the findings were produced and conceptualized. The relevance of the researcher's biography to the interpretations they bring to bear on certain situations is held to be central within certain qualitative traditions (Denzin & Lincoln, 2003) and this approach has informed this research from the outset. Within this chapter a reflexive stance is used to open up the possibilities in terms of the rationale behind the interpretations.

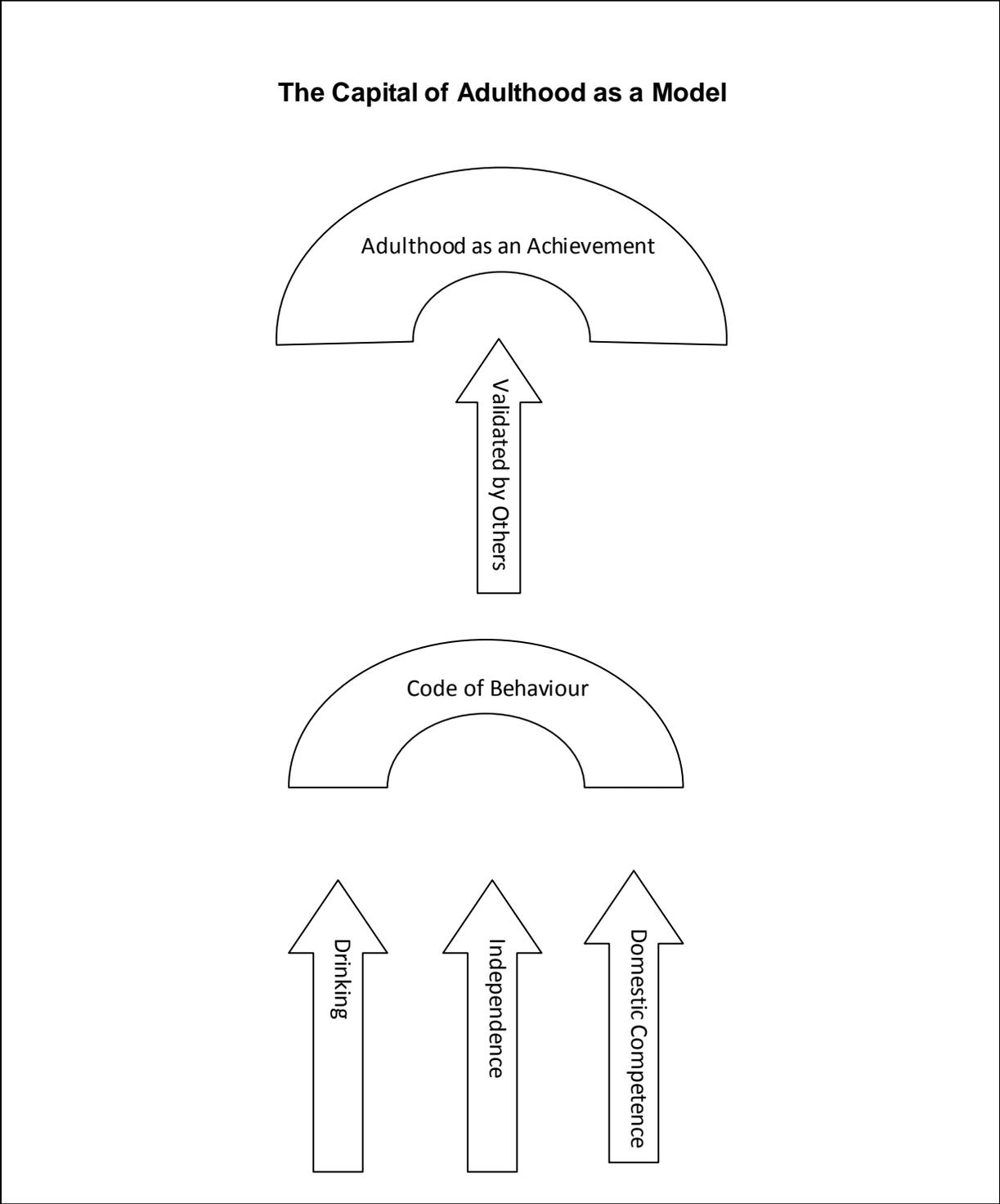
Initially however I have outlined how I have conceptualised the findings from my research into a model which fits the different elements together as a 'related interpretation' of the findings. This has been done for the purpose of making sense of

the relationships between different elements of the perceptions my participants appeared to reveal in relation to adulthood. As outlined in the first of my two chapters on the research findings, five themes emerged from the phenomenological analysis of the data. Although these themes had been delineated, it was not clear initially in the earlier stages of this research quite how they were related to each other and how they would fit together. The conceptual model was created following reflection on Bourdieu's concept of species of capital and which of the behaviours appeared to be deemed necessary to achieve the 'capital of adulthood'. It seemed that three of the themes could come under the umbrella of a 'code of behaviour'. These were drinking alcohol, demonstrating domestic competence and developing independence through achieving financial autonomy and the ability to travel to places without parents or staff. It was through achieving and maintaining this code of behaviour that the end goal – being perceived to be an adult by others – would be gained. As outlined in the following section in this chapter, key to this process of making the transition to adulthood is the validation by others.

Conceptual Model of the Findings

The 'code of behavior' referred to in the middle of the model outlined below relates to the process of acquiring and displaying the behaviours and signifiers of adulthood. The participants in my study appeared to perceive adulthood as a state and status which involved undertaking certain routine domestic tasks. Independence is a significant element and achievement of this state is as a result of travelling in public on your own and having freedom of a kind – even if it was, according to my own perceptions, relatively limited compared to non-disabled peers. Drinking alcohol is perhaps the most vital component in this model however and this was emphasized by my participants who felt – it seemed - that it was necessary to be seen to be drinking by others to legitimate this activity as a marker of adulthood. Once these elements of behavior have been mastered they contribute to a 'code of behaviour' that must be followed in order to achieve and maintain adult status.

Figure 1.1



Marx maintained that society does not consist of individuals but that it ‘... expresses the sum of connections and relationships in which individuals find themselves’ (Bourdieu & Wacquant, 1992, p. 16). Bourdieu – it has been suggested - took this to the extreme with his concepts of habitus and field (Bourdieu & Wacquant, 1992) and it is this emphasis on relationships which has been useful for bringing the conceptions and perceptions as revealed through the phenomenological analysis into a model which clearly describes how these elements fit together. The ‘code of behaviour’ is viewed within this model as a collective term for the actions agents must take within the field to achieve the capital that is associated with the final stage of the process. This is when they are perceived by others to have achieved adulthood. It is a process that is dependent on relations with other agents in the field who will validate the behaviours associated with achieving adulthood through recognising this status. As noted within the chapter in this thesis that reported on the findings from the phenomenological analysis, it seemed to be the perception of the participants in this study that recognition of adult status was not constant and that some people – mostly parents – may not see them as adults. This contributed towards the theme which emerged as the ‘end goal’ as it seemed that adulthood was ‘hard won’ by the participants in my study.

Capital of Adulthood

As noted in a previous chapter, the participants in my study appeared to be very clear about the importance of achieving status as adults. It was something that is not granted automatically but needed to be achieved through gaining the competencies and developing – and displaying - the behaviours as outlined above. One participant described it as ‘what it’s all about’ when asked if adulthood was important –

‘L’ – Yeah. I think so. I’d say it’s very important to. Definitely. It’s what everything is about, moving on. Being independent.

It was framed in moral terms for one participant – ‘G’ - who considered gaining the capital of adulthood in terms of recognition of her status to be evidence that she was a ‘good daughter’. For my participants, adulthood was also associated with obtaining

economic capital. All of the participants in my study referred to the burden of financial responsibilities – paying bills – which would be the cost of achieving the capital of adulthood. As referred to in the phenomenological analysis of the data, childcare and maintaining partnerships were perceived by some of my participants as burdens which could also be viewed as the price of adulthood, although there was a ‘taken for granted’ assumption it seemed that these were an inevitable part of being an adult.

Adulthood was associated with social mobility and for some of my participants it also meant leaving behind a past that may have been troublesome. It was about ‘getting on’ and moving away from a past self who may have been vulnerable and subject to bullying. This desire to create distance from a past self was most strongly expressed by ‘G’, who had undergone successful epilepsy surgery and appeared to want to distance herself from previous behaviour. She expressed frustration that she felt she was treated as an adult within the cultural field of the epilepsy centre and this had changed her habitus, who she was as a person and how she perceived herself, but this was not transferred into a different cultural field when she returned home in the holidays to spend time with her family.

Social mobility was associated with education for my participants and they appear to have the perception that learning and qualifications will lead to the acquisition of economic and other kinds of capital. This would have of course be disputed by Bourdieu himself who viewed education as a way of replicating systems of oppression and keeping the oppressed in their place (Webb et al. 2002). It seemed that my participants were however clear that education would offer them more of an opportunity to gain the capital of adulthood and it seemed that they also felt that they had been offered more of a chance to achieve this through their placement at the epilepsy centre where education to tailored to meet their learning needs.

Cultural Field

A cultural field is a site of cultural practice (Webb et al. 2002, p. 5) and it is peopled by agents with different agendas and understanding, in pursuit of different kinds of capital

The nature of the cultural field in which this research was conducted is a distinctive physical and social space located in a setting with a particular history and geography. The epilepsy centre where this research was carried out has its own language and its own unwritten rules and expectations. There are conventions to be learnt when entering this community. During their induction training, care staff entering the workforce at the centre are taught the official language. They learn about epilepsy - syndromes and seizure types. They complete Safeguarding training, Health and Safety training and begin to learn 'social care speak'. They are then taught the unofficial language of the centre 'on the job' and soon learn to speak in code, referring for example – as noted in Evie's story – to behavioural incidents in short-hand as 'kicking off'. I remember undergoing this process myself as a new support worker, struggling to learn how to say the names of medications that now roll off the tongue. My position in the cultural field has changed considerably since this time and I can confidently speak the language – both official and unofficial.

Bourdieu maintained that language is a mechanism of power (Thompson, 1991) and the specialist use of medical language could be seen as a marker of position for the different agents within the particular cultural field in which this research was conducted. Those who are well-versed in specialist medical language possess a certain kind of prestige associated with medical knowledge. The centre has a multidisciplinary team and employs a range of professionals including doctors, nurses, physiotherapists, psychologists, teachers and care staff. It is perhaps a personal view but it seems that those agents who are most closely associated with medicine are at the top of the hierarchy within this cultural field and those who are at the greatest distance professionally are at the bottom. Who has the power to say what should be happening in relation to the young people in our care can be a contested area. Medical professionals may have specialist knowledge but care staff often know our students better than other professionals as they spend more time with them. Bourdieu's suggestion that a cultural field is a 'battlefield' (Bourdieu & Wacquant, 1992) 'rings true' when applied to a multidisciplinary team where different agendas, priorities and positions create a field that is '...simultaneously a space of conflict and competition (Bourdieu & Wacquant, 1992, p. 17).

Our students also learn a language that is ubiquitous within the epilepsy centre and that will separate them from their non-disabled peers and siblings. There is a certain terminology that will be used. 'Travel training' is the term that is used to describe the process of teaching a young person to travel independently within the local community and beyond. It is a phrase that is used to refer to any use of public transport or even walking to the local village. Young people leaving our care may – in their minds - never catch trains or buses. They will 'travel train' to certain destinations and the process of being 'trained to travel' may never be complete. Domestic skills are routinely taught by asking the young people in the residential units to follow a rota allocating certain tasks within the household and they are typically expected to do these before they leave the unit for college each day. This is the institution known as 'morning jobs' and young people may leave the centre with the impression that it is normal to undertake a particular task each day of the week before leaving the house for the day. They may never learn to spontaneously care for their own living space in the absence of a rota but they know about 'morning jobs'. While I have tried hard to challenge the use of this language and these concepts that I have perceived to be 'institutionalised' in my own practice, it would seem that I have been defeated by the influence of other agents in this cultural field who do not understand why it is problematic to teach language and concepts that would seem alien to young people who do not have learning disabilities. We are teaching 'skills for independence' but not the language it seems.

The cultural field in which this research was undertaken has certain characteristics and like any other the agents who operate within the field are in competition with one another to gain control of the species of capital considered most likely to confer status and control. For the professionals, the possession of specialist knowledge and the professional proximity to medicine appears to confer a certain kind of capital. For the young people in our care, there are certain signifiers of status they appear keen to acquire. The epilepsy centre as a cultural field has certain rules and a specialist language that must be acquired by those entering the field. Interactions within the field will be shaped by the factors that have influenced the development of an agent's habitus – such as medical training perhaps – and the field will in turn shape the habitus which develops as a result of participating in these interactions. The young people in

our care will hold different attitudes, understanding and values as a result of their time within this particular cultural field and so will the professionals who work with them.

Habitus

Webb et al. (2002) define 'habitus' as a –

'... concept that expresses, on the one hand, the way in which individuals 'become themselves' – and develop attitudes and dispositions – and, on the other hand, the ways in which those individuals engage in practices. (Webb et al. 2002, p. xiii)

As noted, the field in which my participants were developing their attitudes and dispositions had certain characteristics and this is reflected in the habitus that they developed and the ideas that they expressed in the interviews I conducted for this research. The young people who come to the epilepsy centre are placed on residential units according to the degree of independence they have acquired. Some will begin their placement on other residential units and 'move up' to others when it is deemed that they have acquired the necessary 'independent living skills'. Assessment prior to taking up a placement at the centre may suggest that particular young people are 'relatively able' compared to others at the campus and they will be placed on particular residential units as a result.

The unit I was managing when I conducted this research – home to the participants in my study – is the 'top of the ladder' in relation to other residential units within the campus in terms of the ability level of the young people who live there. It has been noted that most of the participants in my study felt they had 'made it' in terms of achieving adult status and this was reflected – within this cultural field – by their placement within the most independent residential unit. The attitudes and dispositions – the habitus – that they had developed and which was expressed in the interviews that I conducted suggested that they had been influenced by this experience of being in this relatively 'high status' position when compared to their peers within the campus.

During my time as a care professional working with young people with epilepsy I have met many parents who find it difficult to accept the label of 'overprotective parent'. They have often been through frightening experiences when seeing their child have seizures. Some will maintain close watch over their child – even when they have become an adult – and this sense of constant scrutiny can be difficult for young people such as those in my study. As referred to earlier, my perception is that the young women who took part in my research had exchanged one set of restrictions for another when moving away from home to come to the epilepsy centre. The policies, procedures and practices at the centre are designed to minimize risk for the young people in our care. The activities that are available to them are well-regulated. Reflecting on the cultural field in which my participants were living at the time of this study and the home situations they had come from I began to theorise that the habitus they brought with them and which they continued to develop during their time at the centre was perhaps shaped most of all by the need for precautionary supervision, for risk management and careful monitoring of their health. They would occasionally express frustration at the level of scrutiny they experienced – sometimes with a sense of indignation – but most often it seems to me they accept it.

Reflections on the Influence of Researcher Habitus

Bourdieu called for a 'reflexive sociology', for the 'sociology of sociology' (Bourdieu & Wacquant, 1992 p. 68). The researcher is called upon to examine their own presumptions and influences, their habitus and why they have constructed the research in the way they have. This also resonates with others who would situate the researcher's biography at the heart of the venture and advocate making influences known rather than hidden in pretense of objectivity (Denzin & Lincoln 2003, Dunne et al. 2005). May (2001) calls for guiding influences to be made explicit and suggests that research should not be presented as a 'neutral recording instrument' (May, 2001 p. 33). In order to interrogate why I might have interpreted the data as I did it is necessary to look towards the influences and factors that have been instrumental in developing my own habitus. As suggested in the story of 'Evie/I', my own adolescence was significantly

different and worlds away from the experiences of my participants. I had considerably more autonomy, freedom and privacy than the young people in my study and also faced considerably higher expectations in terms how much responsibility I would take for myself, financially and in other ways. As an able-bodied person I have no experience of disability and the curiosity which has prompted this research inevitably comes in part from the process of reflecting on and comparing my own experiences with those of my participants. The transition to adulthood appeared to be a process that started considerably earlier in northern New Zealand in the late eighties and early nineties when I was 'coming of age' in a very different cultural field. The legal driving age in New Zealand at this time was fifteen. Most young people were in some form of paid employment from their early teens and I was no exception. Although I would now question the wisdom of asking a 13 year old to accept responsibility for infants and small children this was normal within the culture of my teenage years and like my sisters and most of my friends this was my first experience of paid work.

The process of making the transition to adulthood was, as it was for some of my peers, facilitated by the move from a rural community to a city where we began university life. We were the 'kids from the sticks'. We assimilated as rapidly as we could; morphing overnight it seemed, changing the way we dressed, wore make-up, styled our hair, spoke, drank alcohol, what books we read and the films we watched. We were signaling to the outside world that we belonged and – like the participants in my study – we were developing our own 'code of behaviour' attached to the pursuit of capital of a particular kind. While some of my peers were pursuing academic success with a view to gaining economic capital through law and business courses, I entered a different part of the cultural field of university life within the arts faculty, where publication in certain literary journals was, for example, what granted artistic capital.

Alcohol was consumed from a considerably earlier age in the cultural field of my adolescence compared to my participants and there was – it seemed to me - no concern for the need to be seen in places such as pubs, which were largely populated by older men and less desirable for adolescents. Nightclubs were preferred but the legal right to gain entry – at the age of 20 in New Zealand at this time - was not particularly

valued. The ability to gain entry despite no legal right was far more noteworthy and my peers and I were experienced drinkers by the time we finally reached the age when we had the legal right to do so.

By the time I started interviewing my participants, I was a long way from home. I had moved countries several times over and travelled widely. My participants were, however, confined to a 'small world', the margins of which were created by disability. The way in which I interpret the perceptions my participants have of independence – signified perhaps by going to the shops on your own – is influenced by the freedom of choice I have had in relation to where I go and how I live my life. As noted in the opening chapter of this thesis, my own reactions to what I saw as examples of loss needed to be framed in a more reflexive attitude that considered the perceptions, the life-world and habitus of my participants. Where I perhaps saw examples of loss, they saw ordinary life.

In contrast to my participants, I had few choices concerning the acquisition of domestic competence as it was expected that from an early age – in my family at least if not universal in the culture of that place and time - that children would contribute to housework. It is difficult to recall my own perceptions of adulthood in detail but it is fair to say that I did not see the ability to carry out housework to an impressively high standard as a significant marker of adulthood. Certainly as a teenager, I saw it as drudgery and could not understand why many of the women in my family placed such an importance on cleaning their houses - apparently for the benefit of one another for this activity seemed to be focused on impressing visitors - and the 'moral good' that was associated with high standards of housekeeping.

It was clear to be from an early age that this level of and apparent – as I saw it - obsession with 'unpaid work' (Oakley, 2005) was not something I would be taking on myself. It is perhaps not surprising then that I viewed my participant's focus on the acquisition of domestic competence from a different perspective. As noted within Evie's story, young people with disabilities are sometimes considered to be exempt from taking part in household tasks and what is remarkable to them when they enter a residential care environment is that they are expected to learn to look after themselves and their

own physical space. While it was routinely part of my life from an early age to be expected to carry out household tasks, my participants associated this set of tasks with a step towards the much talked about and highly valued process of gaining independence. Thomson (2011) refers to the way in which although ‘... women may take up individualised work biographies, they have the ‘double burden’ of continued responsibility for childcare and the home (Thomson, 2011, p. 30). This expectation that women would work and still be primary caregivers and ‘keep house’ is one that I have recognised within the culture I am from. Reflecting on my responses to what my participants told me in the study, I realized that the beginning point was not when I sat down with a Dictaphone to begin the interviews. The habitus I brought to the research encounter was shaped and developed by experiences many years ago.

Concluding Comments on Bourdieu

Bourdieu maintained that every act of research is ‘...simultaneously empirical (it confronts the world of observable phenomena) and theoretical (it necessarily engages hypotheses about the underlying structure of relations that observations are designed to capture)’ (Bourdieu & Wacquant, 1992, p. 35). The application of Bourdieu’s theoretical framework has been useful in terms of interrogating the data and providing a lens through which to reflect on the possible readings of the situation and the perspective of the many agents involved within the cultural field described. Bourdieu has suggested that ‘To be able to see and describe the world as it is, you have to be ready to be dealing with things that are complicated, confused, impure, uncertain’ (Webb et al. 2002, p 83). The discussion within this chapter has been an attempt to build a better understanding and work through the complications and uncertainties in a way that suggests possible meanings and a means to explore this particular cultural field. It has involved reflecting on the origins of my ways of thinking about the world and how this has shaped the findings and conclusions I have reached.

Conclusion – Chapter Seven – Evie in the End

Poet, sister: words –
whether we like it or not –
stand in a time of their own.
No use protesting
Adrienne Rich

What I Know Now

Evie likes a drink. I could have told you that without the need to carry out the research. However, now I know more about what it means to her. I know she sees adulthood as being about meeting expectations. About showing that you meet expectations.

I now know she associates being an adult with specific areas of domestic competence – mopping the kitchen floor, understanding washing machine settings - and that she thinks adulthood is something she has had to work particularly hard to achieve.

Evie will always remain a puzzle of course - although I do feel that I know more about her now.

The young women represented by the character of Evie in this thesis shared their opinions and perceptions with me and revealed surprises and challenged the semi-conscious certainty I felt when starting the research, secure in the knowledge that I *knew* my students.

The outcome is not as I would have predicted. This was what made the research worthwhile. This is what rewarded the effort and has led to ambitions to carry on working and researching with this population of young people.

Concluding Comments

The purpose of this concluding chapter is to summarise and to draw together the strands of the research, providing a starting point for the next chapter - the one which will actually begin after this thesis has been submitted. This is the work I hope will grow from what has been completed to date. Within this chapter I have also outlined the 'claim to originality' and the 'contribution to knowledge' which I aim to make through this thesis. I have outlined limitations of the study and the lessons learned through the process. I have considered criteria for assessing the quality of qualitative research and have applied the principles developed by Yardley (2008) and Richardson (2003) to my research. The ways in which I intend to disseminate the findings to my participants as well as to a wider audience are outlined. The final points are recommendations that could be taken from this work concerning social care practice and research with this population. This is followed by a final word on the sense of obligation to the young people in my study that has provided both a starting point and conclusion for this work.

Summary

In conclusion, it would appear that the participants in my research had rather prescriptive notions when it came to their perceptions of adulthood. Addressing the research questions that were outlined in the introduction to this thesis, it would seem that adulthood is perceived by the young women in my study to be an achievement. It is achieved through adherence to a particular code of behavior. This code involves domestic competence, a certain kind of independence and entry into adulthood was demonstrated by the legal consumption of alcohol. It would seem that to my participants these things were particularly important and this importance was sometimes communicated as if it were self-evident. Bourdieu refers to the capacity to move across different perspectives and ways of seeing as 'metaliteracy' (Webb et al. 2002) and it was through the process of questioning and attempting to read the common sense understandings of my participants that I was able to begin to gain insight into possible interpretations.

The decision to use IPA as a methodological approach prompted the decision to center the research on the area where my participants seemed to focus their most serious concerns – on the transition to adulthood. As noted, Creswell (1998) suggests that our questions change during the research process to reflect an increased understanding of the problem and in the case of this study it was further reflection and reading on phenomenology that lead the research away from my initial interest in life within the medical model. I also paid more attention to the conversations and interactions I was having with my students on a daily basis within my practice. Part of the development of my researcher identity was learning to ‘listen differently’ to what they had to tell me.

Phenomenology fitted well with the overall ethos of the research in that it focuses on the meaning participants take from their experiences and places their priorities at the heart of the work. It also encourages a reflexive approach that aims to identify and understand researcher bias (Ahern, 1999) and echoes Bourdieu’s call for reflexivity, for researchers and writers to engage in the ‘sociology of sociology’ (Bourdieu, 1992). Bourdieu encourages sociologists – and presumably other social scientists should follow suit – to practice ‘epistemological vigilance’, reflecting on their own social contexts and conditions, ways of thinking and the prejudices that colour their view of the world (Webb et al. 2003).

The young women I interviewed revealed an apparent strong desire to please authority figures. It seemed that they wanted - more than anything else - to gain the respect of their parents and others as sensible, reliable and trustworthy adults with good timekeeping and tidy houses. I identified this as Marcia’s (1966) concept of ‘Identity Foreclosure’ – an identity status that involves conforming to expectations of others. It was however at odds with the apparent rebellion as expressed through the behavior of my participants towards me on occasion in my role as ‘surrogate parent’ and I felt that the need to include this complication in the situation, to avoid merely producing the ‘neat bundles’ of data that might have been the result of a different methodological approach (Wolcott, 2009). Pearson (1993) states that ethnography is a ‘messy business’ but that this is not an impression you would take from many of the research methods texts. He contends that -

'Published accounts of fieldwork are invariably cleansed of the 'private' goings-on between researcher and researched. When the lid is taken off, however, this can be something of a shock' (Pearson, 1993, quoted in Shacklock & Smyth, 1998).

Ethnography has been defined by Tedlock (2003) as an '... ongoing attempt to place specific encounters, events, and understandings into a fuller and more meaningful context' (Tedlock, 2003, p. 165). This was one purpose of the ethnographic fiction that has been included in this thesis. It was written as an extended field note and in the initial stages certainly involved the 'stumbling in the dark' which has been described as perhaps a necessary stage of ethnography (Taber, 2010). It was a way to use writing as a method of inquiry. Richardson (2003) argues that –

'... writing is not just a mopping up activity at the end of a research project. Writing is also a way of "knowing" – a method of discovery and analysis. By writing in different ways, we discover aspects of our topic and our relationship with it. Form and content are inseparable (Richardson, 2003, p. 499)

There was a need to acknowledge the value of what Atkinson & Delamont (2006) describes as 'analytic' ethnography that includes theorizing rather than the presentation of merely evocative work and to this end Bourdieu's concepts have been used as a framework to structure the meaning that could be taken from the findings. I have outlined the characteristics of the 'cultural field' in which the research took place and the influence this may have had on the development of a particular habitus for the young women in my study. I have also considered the 'capital of adulthood' and how the themes that emerged from the phenomenological analysis can be positioned in relation to each other in a conceptual model. The final part of my discussion concerns the influence of 'researcher habitus' in relation to interpretations made of the data.

Margery Wolf (1992) suggests that – 'When human behaviour is the data, a tolerance for ambiguity, multiplicity, contradiction and instability is essential (Wolf, 1992, p. 129). She goes on to argue –

'As ethnographers, our job is not simply to pass on the disorderly complexity of culture but also to try to hypothesise about apparent consistencies, to lay out our best guesses, without hiding the contradictions and instability' (Wolf, 1992, p. 129)

I have included these comments from Wolf (1992) in this concluding chapter as a reminder of the purpose of this thesis. It is an attempt to capture the 'lived experience' of the young women in my study in a way that reveals the complexities and difficulties inherent in this process while also 'laying out my best guesses' concerning what meaning they take from their experiences.

Claim to Originality & Contribution to Knowledge

The claim to originality made by this thesis rests primarily on a relatively novel methodological approach in relation to the sample population. It contributes a more in depth understanding of a group of young people who are not commonly represented in the literature from the perspective taken. As noted, qualitative studies exploring the experiences of people with epilepsy are comparatively rare (Andermann, 2000; McEwan et al. 2004; Raty & Wilde-Larsson, 2011) and - some would argue, including myself – that they have a significant role to play in building a better understanding of the lives of young people with epilepsy.

This study also intersects with learning disability research and one of the purposes of the research is to make a contribution to the growing literature that aims to include the viewpoint of people with learning disabilities (e.g. Walmsley 2001; Chappell 2000). Using a methodology based on asking my participants to reflect on their experiences did create some challenges when researching with young people with memory impairment. However, I would suggest that this is no reason why it should not be attempted. The conceptual model that has been developed from this research could also be considered an original contribution to knowledge, suggesting ways in which young people with epilepsy and learning disabilities may perceive adulthood. It represents – as referred to above – my 'best guess' concerning how the varying elements and themes could be usefully situated in relation to each other.

Limitations of the Study

The most obvious limiting factor concerning this study is one which may render it meaningless to some readers and researchers with a certain type of epistemological and ontological outlook or at best useful merely as a pilot study for a larger scale quantitative survey looking at the issues of concern. This is the question of sample size. It is not possible to begin to generalize across the population of young people with epilepsy and imagine that the findings would tell us something about the experiences of all young people with epilepsy or even those who share some of the characteristics of the sample population.

This was not the purpose of the study however and the value of qualitative research – as argued earlier in this thesis – rests with uncovering and bringing to the surface data that cannot be found by any means. The insight gained into the meaning my participants took from their experiences and understanding of the world would not have been possible with a different research design. It has been suggested that quantitative methodologies can be seen as ‘data condensers’ while qualitative approaches are ‘data enhancers’ (Hesse-Biber & Leavy, 2006). I would argue it is the capacity that qualitative methodologies have for revealing and providing insight into aspects of experience that would otherwise have gone unnoticed that make the completion of studies such as my own worthwhile.

Quality in Qualitative Research

The issue of assessing quality in relation to qualitative research has attracted the attention of a number of writers in this field (e. g. Creswell, 1998; Denzin & Lincoln, 2003). Richardson (2003) has outlined criteria for judging quality in qualitative research. They include making a substantive contribution, aesthetic merit, reflexivity, impact and expression of reality. Aesthetic merit rests on the text being ‘artistically shaped, satisfying, complex, and not boring’ (Richardson, 2003, p. 522). It is certainly my ambition that the work I have produced passes this test.

Yardley (2008) has also suggested criteria that are not dissimilar to those of Richardson with the exception of artistic merit. Yardley calls for 'sensitivity to context' as well as 'commitment and rigor', 'transparency and coherence' and the final principle is 'impact and importance'. Smith et al. (2009) have outlined how Yardley's criteria can be applied to IPA studies and find a good match between a well conducted IPA study and the principles she has outlined. It is not clear in some cases however how an IPA study differs from any other kind of study that is well conducted in meeting these criteria. A coherent argument – for example – will be the hallmark of a well presented study regardless of the methodological approach.

The work that I have undertaken is situated in a distinctive time and place and looks particularly closely at the field of the research from different angles. Commitment and rigor are demonstrated by attention to detail in the process of analysis. Transparency and coherence refer to the way in which the argument has been presented here and the level of success with regard to these criteria will hopefully be apparent to the reader. The final criterion – impact and importance – will be partly dependent on the argument that has been made for the 'scientific rationale' for this work within this thesis. This rests with a novel approach to conducting research with the sample population. If the reader is able to take away a clear idea of why I have undertaken this work I feel I will have met this criterion.

Dissemination of the Findings

As a final footnote to the research, I will be following up with the participants of this study and sharing the outcome of the research. I thought for some time about how to present the findings in a manner which was going to be appropriate and I decided that a face to face meeting with each of the participants was the most appropriate way to achieve this. Darlington & Scott (2002) suggest that dissemination of research findings to people with learning disabilities '...requires serious consideration of the form in which research results are presented' (Darlington & Scott, p. 106).

A written account could be open to misinterpretation and I feel giving a verbal explanation which can be tailored to the person I am talking to would be more likely to achieve a positive closing point to the research experience. It is possible that as several years have passed the participants in my study have few memories of being interviewed. What was a significant experience in my life and one I have revisited countless times during the analysis of the data and subsequent drafting of this thesis was likely to have been a considerably less meaningful event for my participants. It is however important to acknowledge that they need to know the outcome of the research. There is also the curiosity created by the process concerning what has happened to my participants subsequent to their involvement in the study and if they still reflect the opinions and perceptions evident in the research.

My research was a way to tell the stories of the young people I worked with in a respectful and useful manner that would serve the purpose of helping those of us entrusted with their care and education to better understand the young people we work with. The extent to which I have achieved these things is largely dependent on the next stage of the process and how these research findings are disseminated. It is my ambition that the work that results from this thesis will find publication in an epilepsy journal but this may not be realistic given the bias within this genre of publication for quantitative research with a predominantly medical focus. The language in which the findings are presented would have to be considered as despite the views of qualitative researchers such as Richardson (2000) that 'science-writing prose' is no longer 'sacrosanct' (Richardson 2000, p. 509) I would suggest that this would depend entirely on the context.

Quoting Denzin and Lincoln (1994), Goodson and Sikes refer to the 'long shadows' cast over a qualitative research project by the positivist and postpositivist traditions (Goodson & Sikes, 2001). This is perhaps nowhere more clearly exemplified than in the case of a study that looks at the experiences of young people with a diagnosed disorder such as epilepsy. Goodson and Sikes also suggest that opting for a methodology that –

'... deals with, and indeed celebrates, subjectivities, means choosing an approach whose status and respectability are regarded as dubious by many individuals, organizations and institutions whose power means that their opinions can matter' (Goodson & Sikes, 2001, p. 106).

It would be overly optimistic to suggest that the qualitative research methodologies will be embraced in the near future by those working in the field of epilepsy research but there are a small number of researchers carrying out such work and I am certainly motivated to join them. It is my intention to contribute to the methodological arguments concerning how we can represent the experiences of young people with epilepsy and those who have learning disabilities and I am hopeful that this work and further work could help to achieve this aim.

Further Work

This research has been an exploratory investigation into the perceptions of the young women I interviewed and as such has not sought to evaluate present practice in the care and management of young people with epilepsy. It has been intended as a means to open the door for further work, engaging more closely with the 'lived experience' of epilepsy and what it means to be a young woman in this time and place. As argued throughout this thesis, the voices of young people with epilepsy as well as those of young people with learning disabilities are not presently represented in the literature, which could be characterised as being predominantly concerned with treatment and management rather than engagement with their experiences. Further work needs to be undertaken to address this omission.

Three of the themes that were developed through the phenomenological analysis would particularly warrant further investigation. It would appear that attitudes of young people with learning disabilities towards drinking alcohol and what it means to their sense of adulthood has not been addressed to date. Perceptions of what it means to be independent for young adults with learning disabilities could also provide a useful focus and related to this is the acquisition of 'daily living skills' – i.e. domestic competence –

that came through particularly as a theme in this research but which does not appear to have been addressed in the literature. One area that would certainly warrant more work concerns perceptions of epilepsy by young people who have the condition as certainly my study suggests that it is a more 'mixed' experience than most of the literature suggests.

The final area of concern I would see initially arising from this work is the very natural question – what happened next? Within the ethnographic fiction in this thesis was reference to the fact that I often do not know what happens to my students after they leave my care. Little is known of the outcomes for my former students. Do they achieve their ambitions? Are they prepared for the future? Does 'it' – meaning the residential placement – work to provide better outcomes? What happens next for the young people who have been in our care at the epilepsy centre is an area that warrants further exploration.

Final Points

There are points that can be taken from this study and applied to practice for those supporting young people with epilepsy and learning disabilities as well as researchers working in cognate fields. Professionals working with young people with epilepsy need to understand and engage with how they see the world in order to work more empathetically and effectively with them. The 'species of capital' they appear to value most highly – the 'capital of adulthood' – is one that other people may take for granted. Opportunities for young people with epilepsy and learning disabilities to engage in age appropriate activities are important for them to develop a sense of adult identity. There is a significant contribution which can be made through the use of qualitative research methodologies with this population and takes into account their perspective and their agenda.

Transformation & Obligation

On the subject of the concluding stages of a research project, Dunne et al (2009) suggest that -

‘... if you do not feel transformed at the end of a substantial piece of research, you might want to question whether it was worth all the effort’ (Dunne et al, 2009, p. 173).

I certainly feel I have indeed undergone a process of transformation during the course of this research. I am a different and more critical thinker than I was when I began this process. I am more empathetic towards the young women in my sample while I am also – conversely – more aware of why they can be difficult for me to understand and relate to them on occasion. An examination of their habitus and the world in which my participants function led to contemplation of my own taken for granted views and the experiences that have shaped them.

Darlington and Scott (2002, p. 47) argue that it can be seen as unethical not to carry out research in areas of practice where the community invests scarce resources and where there is the potential to harm as well as help people. This is a view I share and I would also state that the type of research undertaken needs to include methodologies that value and promote the voices of those who are receiving professional services. I am not primarily a researcher who has developed an interest in the experiences of young people with epilepsy but a practitioner who has come to research from a need to make improvements in the way services are run and a beginning point is ensuring that we engage with the young people in our care and try to develop a better understanding of their perspective.

I have followed a sense of obligation by way of a lengthy journey to its conclusion in completing this thesis and in doing so I hope I have created a ‘place for talking’. It is a place where the voices and opinions of young women with epilepsy and learning disabilities can be heard and their experiences known. Travelling to this place has involved dialogue with the ideas of writers from a broad range of disciplines and has challenged me on many levels to examine my own ideas and ideals. It has created possibilities for future work. My practice experience has taught me that the care and

education of young people with epilepsy and learning disabilities is often challenging and it can feel on occasion that there are 'unsolvable problems' when it comes to finding the balance between keeping young people safe while also promoting independence. Conducting research with this population and beginning to look for ways in which their care and education could be improved is considerable task. However, what I am left with at the end of the process is what I also felt at the beginning. It is an obligation to try.

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Appendix I University of Sussex Research Ethics Checklist

UNIVERSITY OF SUSSEX SUSSEX INSTITUTE RESEARCH ETHICS CHECKLIST

The Standards apply to all research undertaken, whether empirical or not. When planning non-empirical work, you will need to consider how specific standards and guidelines may best be applied to your research approach, processes and potential impact. Where there is no equivalent for non-empirical work, tick „not applicable“, explaining briefly why in the comment box for each standard.

Standard 1: Safeguard the interests and rights of those involved or affected by the research

1.1 Will you consider the well-being, wishes and feelings, and best interests of those involved or affected?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
1.2 Will written and signed consent be obtained without coercion? Will participants be informed of their right to refuse or to withdraw at any time?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
1.3 Will the purposes of processes of the research be fully explained, using alternative forms of communication where necessary	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
1.4 Where covert research is proposed, has a case been made and brought to the attention of the School Research Governance Committee and approval sought from the relevant external professional ethical committee	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input checked="" type="checkbox"/>
1.5 Does the proposal include procedures to verify material with respondents and offer feedback on findings?	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	N/A <input type="checkbox"/>
1.6 Will conditional anonymity and confidentiality be offered?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
1.7 Have you identified the appropriate person to whom disclosures that involve danger to the participant or others, must be reported?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>

Please add further comments if helpful to clarify the above

Standard 2: Ensure the safety of fieldworkers undertaking fieldwork

2.1 Have you identified any physical or social risks to yourself in undertaking the fieldwork	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input checked="" type="checkbox"/>
2.2 Will you have access to an administrator who will keep a diary of any fieldwork visits and your whereabouts?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input checked="" type="checkbox"/>
2.3 Have you considered how you will collect your material and whether this could make you vulnerable?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Please add further comments if helpful to clarify the above			

Standard 3: Uphold the highest possible standards of research practices including in research design, collection and storage of research material, analysis, interpretation and writing

3.1 Will literature be used appropriately, acknowledged, referenced and where relevant, permission sought from the author(s)?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
3.2 Is the research approach well suited to the nature and focus of the study?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
3.3 Will the material be used to address existing or emerging research question(s) only?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
3.4 Does the research design include means of verifying findings and interpretations?	Yes <input type="checkbox"/>	No <input checked="" type="checkbox"/>	N/A <input type="checkbox"/>
3.5 Where research is externally funded, will agreement with sponsors be reached on reporting and intellectual property rights?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input checked="" type="checkbox"/>

3.6 Will plans be made to enable archiving of the research data?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Please add further comments if helpful to clarify the above			

Standard 4: Consider the impact of the research and its use or misuse for those involved in the study and other interested parties.

4.1 Have the short and long term consequences of the research been considered from the different perspectives of participants, researchers, policy-makers and, where relevant, funders?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
4.2 Have the costs of the research to participants or their institutions/services and any possible compensation been considered?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
4.3 Has information about support services that might be needed as a consequence of any possible unsettling effects of the research itself been identified?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
4.4 Are the plans flexible enough to take appropriate action should your project have an effect on the individuals or institutions/services involved?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Please add further comments if helpful to clarify the above			

Standard 5: Ensure appropriate external professional ethical committee approval is granted where relevant

5.1 Have colleagues/supervisors been invited to comment on your research proposal?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
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5.2 Have any sensitive ethical issues been raised with the School Research Governance Committee and comments sought?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input checked="" type="checkbox"/>
5.3 Has the relevant external professional ethical committee been identified?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
5.4 Have the guidelines from that professional committee been used to check the proposed research?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input checked="" type="checkbox"/>
Please add further comments if helpful to clarify the above			

Standard 6: Ensure relevant legislative and policy requirements are met

6.1 Do you need an enhanced Criminal Records Bureau check?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	N/A <input checked="" type="checkbox"/>
6.2 Are you certain about implications arising from legislation? If not has contact been made with the designated officer (Chair of the SI Research Governance Committee)?	Yes <input checked="" type="checkbox"/>	No <input type="checkbox"/>	N/A <input type="checkbox"/>
Please add further comments if helpful to clarify the above			

Appendix II – Participant Information Sheets

‘This is a Place for Talking’

Participant Information Sheet

What?

I want to do a project to find out more about you and how you feel about things in your life. In particular, I want to know how you feel about growing up and becoming an adult while you’re at the (epilepsy centre).

Why?

I think it is important that we know more about our students at (the epilepsy centre) and that other people know about how you feel about your experiences.

How?

I’d like to interview you a few times. I will write it all down and try to work out if there are any patterns that tell us more about your experiences.

When?

I’ll want to talk to you over the next few months. We can make a time which is good for both of us.

What if?

You change your mind...

Even if you agree to take part, you can change your mind at any time. You can also decide that you don’t want to answer some questions.

Something sensitive comes up...

If we talk about something which upsets you, there are people you can discuss any issues with. You can talk to me, to your keyworker or to (name of the psychologist) or to (name of the safeguarding lead).

Appendix III – Participant Consent Forms

'This is a Place for Talking'

Consent Form

Dear _____,

I am doing a research project looking into the experiences of young people at the (epilepsy centre). I would like you to take part in this. This project is sponsored by the University of Sussex.

As I said in the information sheet, it is important that you understand that -

- It is your choice to take part in this project.
- You can say if you don't want to answer any questions.
- You can stop participating at any time.

Thank you,

Vee

Please sign this form if you would like to take part in this study.

_____ (signed)

_____ (printed)

