# Women with Learning Disabilities in a Secure Hospital Setting and their Experiences of Seclusion: Adopting a Feminist Case Study Approach

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#### **Thesis Abstract**

#### **Title**

Women with learning disabilities in a secure hospital setting and their experiences of seclusion: Adopting a feminist Case Study approach.

#### Aims

- To find out how women with learning disabilities within secure mental health hospital settings in the United Kingdom viewed their experiences of seclusion. It set out to capture the unique experiences of women with learning disabilities by exploring and analysing their own accounts.
- To inform and contribute to the current policy drive and debate regarding the use of restrictive practices across mental health and learning disability services and include the views of the participants themselves.

# **Methodology and Methods**

The study has been designed within a feminist framework which has shaped and guided the way in which the literature review was conducted and then also the methodological design and data analysis.

This study adopted a qualitative Case Study methodology that allowed different sources of data to be collected and analysed. Semi-structured interviews were used to gather data from fifteen women in two different medium and low secure hospital settings. These data were triangulated with case notes, observations and discussions with care staff. Data were analysed thematically.

# **Findings**

Thematic analysis identified three themes which showed gender nuances in seclusion use for women. The themes were:

- 1. Cultural construction and language
- 2. This is me Self-perception and what defines the female and learning disability experience

3. Hierarchy, support and power – the importance of staff

#### Key findings included:

- A-typical and multifactorial nature of seclusion differing perceptions and perspectives on the reasons seclusion is implemented
- The importance of language and its misrepresentation of perception. Cultural language
  embodied by the institution is also adopted and used by the women to express themselves
  and to describe their experiences. This is reflective of the institution but not necessarily
  reflective of the way in which these women themselves feel.
- The importance that the women attach to having the support of familiar, skilled staff. For
  the seclusion experience to be and to remain a therapeutic experience then familiar staff
  need to be utilised with significant therapeutic skills.

#### **Discussion and Conclusion**

The findings of this study offer a unique contribution to knowledge by providing insights of the experiences of seclusion from the perspective of women with a learning disability. Use of a feminist lens brings to the fore the role of language and power. This leads us to consider how our current policy, legislation and guidance serves the women and the way in which they experience seclusion. Recommendations for practice change are offered based on the narrative of the women, the female clinical presentation and viewing our current debate on the use of seclusion through the experiences of these individuals.

#### **Implications for Practice**

- The skills and consistency of staff support is vital for individuals experiencing seclusion. It is
  therefore important to ensure that this forms part of care planning, risk assessment for
  seclusion and other associated restrictive practices.
- Staff need to understand the perception of seclusion and experience of seclusion of the individual person. For some the need to feel safe and supported around de-escalation is vital.

Staff need to understand that the person with a learning disability who uses institutional
language within the hospital culture is not necessarily demonstrating their true
understanding or experience of seclusion. Language has the potential to act as a barrier to
understanding service user perception.

# **Implications for Future Research**

- The methodological approach taken through the interpretation and use of Case Study
  methodology allows for the individual experience to guide our knowledge and insight into
  current practices. This research could inform future approaches to enquiring into the lives
  of people with a learning disability, encouraging participation and an individualised
  approach that enables us to better understand their experiences through primary qualitative
  research.
- This study discovered that seclusion could have a different meaning to those experiencing it from the way in which policy and process has been steered. Seclusion to some was shown at times to be somewhere that women could retreat to and yet to some reinforced an already established power imbalance that they had always accepted and experience on account of their past experiences and at times, their gender. Future research can explore this subject further through involvement of the participant in deconstructing the concepts of restrictive practice and inspire a confidence to involve those in studies whose health may fluctuate over allocated research time.

This research can inform the way in which we faithfully capture the voices of those less heard in research with learning disabilities.

This research contributes to our current knowledge by highlighting gender differences which call in to question processes of seclusion and the way in which these are implemented for both women and people with a learning disability. The research demonstrates that change is required through the way in which women perceive seclusion both as punishment but also as a safe space through which to escape difficult experiences within the ward environment.

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# **Author's Declaration**

I declare that this is my own work; it has not been submitted in substantially the same form for the award of a higher degree elsewhere.

Helen Jones (August 2022)

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# **Chapter 1: Introductory Chapter**

#### 1.1 Introduction to the research topic

This research study will explore the experiences of women with learning disabilities and the way in which they understand and interpret their experiences of seclusion. The Mental Health Act Code of Practice, (DoH 26:103) defines seclusion as, "the supervised confinement and isolation of a patient, away from other patients, in an area from which the patient is prevented from leaving, where it is of immediate necessity for the purpose of containment of severe behavioural disturbance which is likely to cause harm to others". The focus here is quite clearly on isolation, supervision and confinement. Anyone placed into seclusion would not be able to leave of their own free will. The process usually involves physical restraint prior to and often as seclusion begins where someone will be held by more than one person to prevent them from harming themselves or others. A locked door as well as the presence of staff would also prevent the person from leaving the room. There are also usually a set of seclusion rules that apply while in seclusion. These rules will dictate physical and psychological observations of the person, the layout of the room and access to particular items, facilities or activities while in the seclusion room. Seclusion ends as soon as a multi-disciplinary review deems that it is safe to do so and as soon as the person is free to return to the main ward environment. This study puts the lives of the women, all of who have a diagnosis of a learning disability and associated mental health disorders at the centre. The focus on seclusion allows us to hear their perspectives through the lens of restrictive practice. This chapter will discuss the concept of seclusion and the research question, the population to be researched and also go on to define my positionality as a researcher which has then led to my choice of a feminist framework within which to design and conduct the study.

# 1.1.1 Finding the research topic

A systematic review carried out by Chieze et al. (2019) to include international studies as well as UK studies highlighted findings that showed the negative effects of seclusion, showing links to past traumatic experiences in a person's life and also that seclusion may be more widely accepted due to its perceived non-invasive nature as opposed to physically holding or restraining someone for a period of time. This study advocates for further qualitative studies to explore some of the links

between the themes they found in their review. Mind (2015) also show that seclusion goes hand in hand with other restrictive practices including the use of medication to control and suppress aggression or particular behaviour as well as physical restraint. A CQC report in 2020 showed that many of these measures with adults with a learning disability in the UK are used inappropriately and that often people are detained in hospital and receiving care and treatment not appropriate to their long term health and welfare. The debate around whether seclusion should be eliminated rather than simply reduced has been going on within psychiatric academic circles for two decades now (Bowers, 2010; Happell, 2011) but often the consideration for people with learning disabilities is shrouded in policy guidance or opinion, meaningful certainly but not necessarily considered within the wider evidence-base. Equally, women and their experiences of seclusion are not included in the discussion to the extent that men are.

In 2013 I concluded my MSc dissertation research study as part of an MSc in Forensic Mental Health Studies. Between 2002 and 2011 I had studied and worked across different forensic secure mental health services for individuals with a learning disability. While working as a registered learning disability nurse I had mostly been employed within female secure services and this population was interesting to me. I decided to conduct a small study exploring the support needs of qualified nursing staff working with this particular population as perceived by them. The study focused on the support staff thought they needed when dealing with high levels of violence and aggression. I travelled to a site in England which delivered low and medium secure level care to both men and women and after analysing the responses from questionnaires sent out to staff working with the women there I then hosted focus groups for staff and focusing on themes that had begun to emerge following analysis of the questionnaire data. It became apparent that working with women, mirroring my own experience was often unique and tangibly different to working with men. This often related to the levels of emotional pressure the women appeared to cause to staff as well as incidents of aggression which may last longer and therefore elicit different responses from staff than nursing men might. One area that interested me greatly was when the topic of seclusion was discussed. This was an emotive topic and clearly caused distress to staff as they talked about their decision making capabilities, the stress that long lasting violent incidents caused to them and feelings of guilt also. What interested me was that I had never made the decision to seclude anyone during my time working as a nurse and that was purely for the reason that the hospital I had worked in did not have a seclusion room at that time. I had worked at other hospitals where people were nursed in seclusion and I had participated in this and witnessed people being put into seclusion. I had nursed someone in a sort of "make-shift" long-term segregation room after a significant violent incident which put people at immediate risk and warranted transfer to a higher level of security and

this arrangement was put in place while that transfer had been arranged. After the focus group I simply wondered, if this is so difficult for staff what is it like for the women themselves to be put into seclusion? What does seclusion mean for them? There is no recent study that specifically asked this question within the UK although a preliminary review of literature highlighted a current debate around the need for elimination or reduction in seclusion practices and this was also driven by a changing approach to treatment of those with learning disability and mental health disorders within hospital settings including Positive Behaviour Support (Emerson, 2011), Dialectical Behaviour Therapy (Linehan, 1993) and SafeWards (2013). These changes are being shown to highlight that there are different approaches to caring, treating and nursing those detained within secure services. An evidence-base shown through systematic reviews is forming a discourse around the benefits or problems associated with using seclusion among other restrictive practices. It is important that the experiences of smaller, minority groups that will be ultimately affected by practice drive and change are heard and responded to.

#### A note about terminology

Although I write about my participants as 'having' learning disabilities or as 'learning disabled', I acknowledge these to be complex and occasionally controversial descriptions. Today, and across different nations and services we will hear terms that are different such as intellectual disability or developmental disability. As someone currently still registered as a learning disability nurse I have chosen to use the term learning disability over others. Simpson (1999) gives an overview of the history of definitions of learning disability, and provides a critique of the classification mechanisms in use at particular times as moving between physiological descriptions to social manifestations. The services that these women are treated within are deemed as specialist services due to staff possessing specialist knowledge around those who cannot be easily or well treated and cared for within mainstream mental health services due to level of vulnerability, cognitive functioning and ability to engage in particular treatment programmes.

The term learning disability is currently debated in terms of its appropriateness to the group of individuals it represents. There are various similar definitions (DoH, 2001; WHO, 2016) that agree on the parameters that define this terminology. However, there is potential confusion in that the term is used differently in different areas of the world (Gates and Mafuba, 2016) and continues to cause some difficulty in wider society, particularly with the emergence of focused educational professional support and the similar term of learning difficulty / disability used within that arena. The term intellectual disability has begun to be more widely adopted and at times used interchangeably even within the UK (Mansell, 2010). While the term learning disability continues to be a defining and

understood term for those who fall within accepted parameters including level of social functioning, age of onset and the ability to learn and process new information, the term intellectual disability for example, is less widely understood, certainly within the UK and also continues to cause some confusion amongst professionals who to date have not yet been provided with that key rationale for change (Cluley, 2017).

#### An overview of secure services and the UK

Secure services within the UK provide hospital-based care and treatment for those who require mental health provision but are deemed a risk to themselves and to the public should they be treated within the community. All adults over eighteen detained and provided care within a secure service will be diagnosed with a categorised mental disorder that may include mental illness, learning disability and / or personality disorder (DoH, 2015; updated 2017). Those cared for in a secure hospital will usually be subject to detention and treatment under the Mental Health Act (1983) and many will have been referred to hospital for treatment through the criminal justice system. Therefore, many of those within secure services will be offenders with a diagnosed mental disorder as defined in the Mental Health Act (1983). However, many people are treated in hospital under a civil section which means they have not committed an offence or have not been prosecuted. This is more likely for women and also those with a learning disability (Home Office, 2007; DoH, 2012) where historically, suitable services have not always been available or able to support in the right way in the community (CQC, 2020).

Secure services within the UK have generally been categorised as either High, Medium or Low secure. The definitions that differentiate these are loose and do not refer primarily to the requirements of the physical security but to the level of risk that the individual poses to either themselves, others and the public. The level of security will be chosen dependent on whether this risk is immediate, grave, public and how long treatment may be required for. Involuntary admission to a secure service is governed legally by the Mental Health Act (1983, amended 2007). Therefore individuals may move between the levels of security depending on availability, current risk assessment and any particular directive of the courts. In 2021 a relatively small-scale study by Tomlin (2021) highlighted the prevalence and comparison of forensic in-patient provision across European countries. At that time the figures provided by NHS England showed around six and a half thousand beds across England and Wales (Tomlin, 2021).

#### 1.1.2 Rationale underpinning the research enquiry

Virginia Woolf regards her position as a female writer within a male world. She recounts the female experience in one of her seminal works of being at a University and a man looking towards her on campus with a look of "expressed horror and indignation" (1929: 258). She comments upon the tendency to define humanity as male and that all she knows and even challenges are relative to man. Other female writers, e.g. Dorothy Smith, who was writing later than Woolf, also commented on the fact that what we knew was essentially what men "knew" and wrote for each other at the exclusion of women (1987). A history of healthcare and gendered healthcare is well documented (Green, 2008). However, this observation by Woolf struck a chord in so much that, for me, it echoed the development of female services providing care for mentally disordered females over the years. That is to say that these services were most likely designed for a male population given that females were nursed within male wards in isolation (Aiyegbusi, 2002) and this therefore has potentially influenced much of the limited literature that has been written about this relatively small group of individuals. I do not just wish to challenge these older viewpoints, but that I would like to ask "new" questions while placing the lives of the women I choose to research at the centre of this. It is also imperative that I adopt a suitable model of research due to the fact that I am also aiming to tell the stories of women who have a learning disability which can often mean it is harder to for them to tell their story due to communication and access difficulties (Mercer, 2002).

Following the Winterbourne View enquiry back in 2012 (DoH, 2012) we had the Transforming Care agenda which aimed to tackle the problem of people with learning disabilities and autism who were wrongly detained and being nursed within secure environments. The Transforming Care agenda aimed to get people back to their homes, their communities and their families and to be supported to have good care and support in order to prevent readmission. Hospitals and wards began to receive timeframes in which people should be moved out of the hospital environment and appropriate care packages be built and put in place for those individuals. Understanding the lives of women with learning disabilities and how they experience restrictive practice can help to inform the way in which we can work with them to support this agenda. CQC reports from 2019 highlight the continued use of seclusion and other restrictive practices for those with a learning disability (CQC, 2019) while other studies such as Long (2015) highlights gender more generally as requiring something a little different but is unable to determine within that particular study what that actually is although that it may lean more to the relationships cultivated by staff and the need for feeling safe. Seclusion is a contentious issue and debate, with elimination being sought but alternatives not

always preferable, for example medication. If the female experience is different, then it is important that is explored.

#### 1.2 Thesis Overview

#### 1.2.1 Aims, objectives and research question

The overall research question I am going to address is what are the experiences of women with a learning disability who are detained within a secure hospital setting through exploration of their experiences of seclusion in particular?

The over arching aim of this research are:

#### Aims

- To find out how women with learning disabilities within secure mental health hospital settings in the United Kingdom viewed their experiences of seclusion. It set out to capture the unique experiences of women with learning disabilities by exploring and analysing their own accounts.
- To inform and contribute to the current policy drive and debate regarding the use of restrictive practices across mental health and learning disability services and include the views of the participants themselves.

#### 1.2.2 Structure of the thesis

The introductory chapter provides the reader with an overview of the study aims, ontological and epistemological positionality of the researcher and then to introduce the research paradigm. I will discuss concepts of cultural relativism and social construction and discourse in relation to reality, knowledge and power and show this through my own experience and values as both a learning disability nurse and a female researcher. This will then lead me within the same chapter to introduce the concept of feminism, feminist research and its application to a framework / paradigm that will overarch my whole study.

Chapter Two provides the reader with an overview of current and other relevant literature relating to the research study. The literature has been chosen based on the qualitative leaning I will demonstrate through my values based epistemological discussion as well as the feminist lens I have

argued for in the introductory chapter. This is reflected through my choice of search criteria, hierarchy of evidence and deconstruction of the concept of seclusion within existing literature.

My methodology chapter begins with a revisiting of the feminist framework in order to then clearly show and justify my methodological approach to conducting the research study which is that of qualitative Case Study research. I discuss the reasons this approach has been used within this study and then how my study and data collection have been designed within this, namely the use of semi-structured interviews, observations, inclusion of data from case notes. Throughout this chapter, the overarching feminist framework are evident through the use of reflective accounts, consideration of the cultural and gendered aspects of the evidence presented and the approach I took myself within the interview process. The methodology chapter also includes sub-sections outlining the ethical processes required to be undertaken and the adaptations made to ensure informed consent and adherence to laws governing information and data. The chapter concludes with a look at thematic analysis as outlined by Braun and Clarke (2021) and once again how this is an appropriate method of data analysis based upon my framework, methodological and data collection approach previously shown.

I will then present the hospitals, or host sites, the women themselves as case studies and my own observations and reflections on being introduced to them for the first time. The reflexive approach discussed earlier in this chapter through examples of writing undertaken immediately preceding and proceeding interviews are provided within accompanying appendices.

My results chapter then provides an overview of the coding and theming processes as outlined by my chosen thematic analysis model. Once again I reference how my overarching feminist framework has been included during these steps. My themes are presented based first upon the interviews with the women themselves and the transcriptions from these. This is then triangulated with additional evidence from both my own observations, clinical notes and discussion with certain clinical staff.

Once the themes from the thematic analysis have been discussed and presented within the results chapter my final chapter discusses each of these in turn and consider these within the context of what the women's stories tell us about their experiences of seclusion and of being in hospital. Further literature will be explored as I make sense of the data and present findings and recommendations around future practice. Finally, the thesis is concluded, bringing together findings, interpretations and recommendations are made for future practice and research.

#### 1.3 Researcher Positionality

Positionality within qualitative research is now often viewed as affecting every aspect of a research study (Holmes, 2020). It is viewed by some as encompassing both the objective and the more fluid, subjective aspects, inclusive of the lived experience and values of the researcher themselves (May and Perry, 2017). It is important to explore the way in which I view the world so that I can understand my personal integrity, social and political influences and the way in which this will shape and therefore influence the research approach and subsequent findings.

I will outline the role and importance of my background as a registered learning disability nurse and the values I hold as core in that respect. This will therefore begin to demonstrate and form the outline of my ontological position and the framework that will guide this study and its methodological approach. Incorporating the feminist approach but perhaps more pertinently here, the social constructionist perspective in relation to my own positionality has meant that I have always found my world shaped by the consciousness I have in relation to certain ideas, concepts and that has then shaped the way in which I have interacted in my work, with intentionality, as defined by Crotty (1998: 44). This is where my own cosmological position or my own origins are important to document here in relation to how this study has then been designed and implemented.

I became a learning disability nurse at the age of twenty-five. I did not plan this route upon leaving secondary school and then leaving home for the first and last time at eighteen to go to university. I chose to study history but growing up in the north east of England, learning disabilities had already become a part of my upbringing and experience.

My parents met at a local hospital for people with "mental handicap", which was the term used at that time in the mid-1970s. My dad was working and training as a clinical psychologist and my mam was in a more administrative role at that time though later went on to be a teacher for children with autism. I spent time with my dad for work experience while at school, working in an NHS community team with nurses, Speech and Language Therapists and psychologists. I enjoyed this immensely yet at that time I had no thoughts to pursue this area as a career choice. Working in care homes while at university led me back towards learning disability nursing. Nursing felt right as I always felt that fundamental daily care was something I enjoyed being part of as much as the additional therapeutic or assessment work.

Yet nursing and the area of learning disabilities itself does not fully explain or indicate the methodological approach and feminist stance I have chosen to take as an early and developing researcher. This is certainly reflective of core values generally adopted by those aiming to improve

the lives of others and to advocate for them as part of minority and often ignored groups in society. My approach to my research also reflects the values instilled in me by my own experience growing up. I believe in a fair society, where everyone should be valued and supported. I believe that we should listen to others, respect others but also challenge bullying, repression, and unfairness. To disregard anyone because of gender, educational ability, social status or any other demographic is unacceptable to me as an individual. Through my experiences, relationships and learning I have also developed skills in reflection which I continue to improve on and that allow me to keep trying to uphold these values every day. This is what makes me suitable to conduct this research study in the way that I have. What makes me qualified to conduct this research as well as being suitable is that I now have over a decade's experience of making that transition from learning disability nurse to academic. I have engaged with research as part of my own teaching development during this time and also begun my own journey as a researcher, with particular focus on the lives of women.

Therefore as a result of exploring my cosmological position and through ongoing reading and reflection, there are some key elements which helped to explain my own position as the researcher and therefore also supported me to begin this process. The beginning of my ontological exploration was that I had begun to consider myself and therefore my positionality and initial attempts included the list below:

- I consider the therapeutic relationship / milieu as very important and would like to reflect this in the research process.
- I am essentially an educated female working within a university setting and from an
  educated left-wing family which influences my political thoughts and the way I conduct
  myself within academic circle.
- I worked within these types of secure hospital settings for a number of years as a qualified learning disability nurse and feel that this knowledge and background will feature within the research process.
- I often feel the need to advocate for those I nurse, which has at times left me feeling quite antagonistic and willing to challenge the status quo. This may need some reflexive thought while conducting the research and listening to the participants.
- I often identify with the minority and can be swayed by their situation.
- I am potentially vulnerable to the traumatic experiences that I may be told of during this research study. I have found debrief and clinical supervision skills useful throughout my career.

- I am female, am a mother, divorcee and a partner within a heterosexual long-term relationship. This will influence my view of the female experience.
- My current work role requires me to teach and develop critical thinking.

As soon as I decided to conduct research around the experiences of women with a learning disability in secure care and those who nurse them, I instinctively felt that my methodology and guiding frameworks needed to directly reflect their "position" within such services as well as allowing me, the researcher, to establish my own position from which to begin conducting this study and gathering data. In addition to this, the way in which I have chosen to write also reflects my chosen positionality and the role I would play as a researcher in this particular study. When I present the methodology chapter I will refer to Robert Stake. Stake (1995) believes that stories of the researcher journey are just as important within the research and that researchers represent themselves through their presentation of the participant also. This also allows for the writing within the earlier parts of the thesis to show the process of the research journey as well as going on to present the outcome of the study within the later chapters of the thesis.

All of the elements listed above played a part in the design of my research. They influenced the way I considered whether theoretical research frameworks and methodologies would suit how I wanted to gather my data and then go on to analyse any findings. This is shown later in the thesis when I discuss the potential paradox between current practice guidance on seclusion and how that influences the way in which women might experience it. It also means that reflexivity as a tool within my research framework was always going to need to be present.

As a learning disability nurse, and as a nurse generally, I am constantly seeking to reflect upon my learning and clinical experiences. The concept of reflection within nursing is built primarily on generating new learning and improving care. This is a skill that nurses seek to establish and then refine throughout their career (Oleofson, 2012). The need for self-reflexivity however is more important than ever when working with people who may have a learning disability and / or other associated conditions within research as it allows the researcher to be cognisant of their own impact as well as to understand the responses they may experience during research and therefore the interpretations they make. With regards to this study it is important I can identify personal bias and how my own positionality may affect the data collection process and then its interpretation.

Considering the above list and my own values base I am conscious that I may be seeking to challenge care that the women in my study may experience and should be mindful therefore of how I interpret their viewpoints and the information they provide. Holmes (2020) reminds us that reflexivity

throughout research processes will allow us to realise that our subjective views, values and impact may change over time and that being reflexive allows for us to see that. If we are unable to recognise such changes as well as the impact any fixed views or preconceptions may have on research then our research is less likely to be validated, robust and ultimately ethical (Sultana, 2007; Holmes, 2020).

Over the past few years alone the UK has been made more than aware of institutional abuse which has now served to shape current health provision and services (DoH, 2012). While these kinds of events not only affect the policy guiding and shaping our working environments, we are also more keenly scrutinised as professionals and as individual practitioners (NMC, 2015). Nursing revalidation practices are one example of this type of scrutiny and therefore advocating the need for a more self-aware, reflexive nurse practitioner.

So, as highlighted more extensively below, it is important that I am able to position myself ontologically and then epistemologically in order for me to really conduct my study in the best way so that I am staying to true to those involved and to ensure that the aims of the research study can be remembered and adhered to during the course of this research process.

#### 1.3.1 Ontology

Ontology is essentially concerned with the nature of reality and the nature of being. Ontological positioning defines the questions we ask about what exists and then leading on to epistemological exploration of how we find out and know. Ontology is to explore what relationship exists between the world and our "human understandings and interpretations of the world" (Braun and Clarke, 2013). Bryman (2008) ascertains those ontological assumptions within social research cannot be separated from the way in which research is then approached and conducted by the researcher. He maintains that it is these ontological beginnings which lead to the formulation of questions and then the methodological approaches that are taken. Here I will show how I view reality and to show my positioning as to whether reality exists completely separately from human practice, systems and general understandings of our world, or whether the two are interlinked in some way and cannot be separated from the way we do and therefore think. This discussion will reflect my perspective.

Tebes (2005) describes the one end of this spectrum of considering reality as a "mind-independent truth". Positioning oneself here would assume that reality does in fact exist beyond what we think and do, and there will be this existential truth which we may not even fully understand. This is generally termed "realism", while the alternative view which views reality as dependent upon

human interpretation and experience is known as relativism. There is no one truth and that to some relativist minds, this truth is in part socially constructed (Burr, 1996). Those who position themselves more within this relativist approach would also argue that reality therefore would change across time and across different contexts and cultural diversity. A critical relativist approach would assume that the researcher would never be able to eradicate those nuances and differing perspectives in order to ascertain one unequivocal truth (Cooper, 1987). The researcher accepts they are there and therefore questions and research approaches are formulated to embrace this underpinning belief. More recently though discussions emerge that argue critical realism and relativism are not as far removed given that in some circumstances the impact of certain conditioning is undeniable although that truth and reality may be beyond what we can define (Lawson, 2003; Al-Amoudi and Willmott, 2011)

In order to begin exploring my own ontological assumptions and positioning I had to consider how I interpreted and viewed reality and the knowledge I have of the world around me. I can do this both professionally and personally. It is then that I can define the position that I most closely identify with.

A recent example is that despite "the science" and the fact that we know people have died, some people in our society remain sceptical as to the reality and nature of the coronavirus. More recently this has been played out in the media through anti-vaccination protesting and denial. This has directly affected my own world professionally requiring me to inform student nurses that they are no longer able to continue on their course due to not having the vaccination. This for whatever reason is their reality or their version of reality. Yet to dismiss this entirely would assume that my reality is more meaningful and important and instinctively this does not feel right. However, I do accept that some external knowledge must be taken into account in order to produce some meaningful change (Rogers and Rogers, 1997). To claim that some knowledge and experience is perhaps "authentic" would support to bring about change as assuming all versions of the truth are equal would be to deny that opportunity.

This leads me into my professional discussion. As a learning disability nurse, I of course seek to uphold the Code of Professional Conduct (NMC 2018) at all times, in both my personal and professional life. I can fail personally but very much try not to professionally. I work in a person-centred way as defined by learning disability nursing leaders such as Helen Sanderson and Emerson in the 1990s. In turn their work had been based on seminal work by Wolfensberger (1970) and O'Brien (1981) who set out principles of "normalisation" and enshrined in important concepts such as community, collaboration and consent (Lewis & Sanderson, 2011) and very much adopted within

the history of the learning disability nurse. This was the era that saw the development and evaluation of person-centred planning (PCP), and the important publication of the Valuing People White Paper in 2001 (DoH, 2001). For the first time the Department of Health set out the principles for the introduction of person-centred plans for people with a learning disability and the accompanying Research Initiative which aimed to review the impact that this would then have on the lives and experiences of people with learning disabilities.

This was new in that it now meant that services should be tailored to the individual and not the other way around and people with learning disabilities should have their voices more readily heard and express how they wanted to live their lives. The Community Care Act (1990) a decade earlier had aimed to see the closure of the more traditional institutions and hospitals that housed people with learning disabilities and associated mental health and physical conditions. When reviewed in 2005 (Robertson et al. 2005) the impact of PCP was overwhelming in terms of its positive impact on people's lives but the review also highlighted inequalities within different groups and communities as well as the need for consistent ongoing funding and support to services in order to deliver the kind of person-centred care that the 2001 White Paper was advocating.

Legal advancements such as the Mental Capacity Act of 2005 enshrined in law the way in which I had certainly been practicing already for a number of years. Consent and capacity and the exploration of this within everyday working life became paramount. Always working from the principle that as far as possible people with learning disabilities and mental health needs should have a say in their own care and be supported to make their own decisions where possible was key to the way in which I approached care as a nurse. As a community learning disability nurse much of my work within the early 2000s was to support in the initiating and development of the person-centred planning process with individuals and their families. This was very much carried out within the framework of the multi-disciplinary approach to care. However, person-centred plans did not often have the impact they intended if services could not then meet those needs or requests (DoH, 2009). This means that I believe there is no one right answer to a question and that information can be interpreted in many different ways dependent on the perspective and the evidence-base being considered.

Having witnessed and experienced conflict between medical professionals and families it is clear that reality is not objective and can never really be the same for everyone. However, the knowledge that people have is also influenced greatly by their own experiences, values and background. It is their knowledge and therefore their version of reality at that time. My own practice and the way in which I approach practice is that I do believe that some authentic knowledge has previously been generated in order to support and develop processes we use, however, I do not believe in stifling

people's own beliefs or alternative ways of approaching things through the use of such processes. Standardised approaches, for example, an assessment tool format, may be considered best practice, but a person-centred planning approach would also suggest that these be adapted in order to support individual needs. This is evident within the assessment of mental capacity whereby key principles are key rather than the assessment tool that is utilised, an approach shared by those professionals working within learning disability practice and continuing to generate new ways of working.

Positionality "reflects the position that the researcher has chosen to adopt within a given research study" (Savin-Baden & Major, 2013: 71). Holmes (2020) discusses the importance of reflexivity within developing a positionality statement, particularly for the novice researcher and undertaking qualitative research but also cautions that being reflexive does not guarantee good research on its own. Reflecting on my own professional background and values as well as the importance that I place on the individual experience, I believe that while individuals may experience life and reality differently and uniquely that we have constructed narratives and norms that either enable or prevent people from thriving or fully understanding their experience. This reflects the theoretical lens of social constructionism, that what we know is often dependent on shared, cultural ways of thinking and doing that change with time. However, this does not mean that this is the way that individuals or even groups of individuals really experience the world.

Burr (2006), taking a view from Gergen (1985) acknowledges that the concept of constructionism is broad but that key principles apply. These include taking a critical stance towards knowledge and views that we take for granted, acknowledging changes due to historical and cultural specificity and the importance of knowledge in facilitating social change. From my own positionality discussion previously this is important to me as I welcome the changes that have occurred in terms of our views towards disability and the changing discourse around the value that those with a disability have within our society, a view that was not prevalent within our own western culture decades ago. Social constructionists realise the importance and sometimes reliance on process and political and social frameworks to represent changing knowledge and values yet should continue to challenge these when new viewpoints are raised.

Key writings and thinkers that are credited with bringing about the term "social constructionism" include Berger and Luckman (1966) and Foucault (1982). The latter is particularly important in my own enquiry into positionality as a researcher as Foucault along with general social constructionist theories outlines the importance of discourse as key in social change and the influence of language in constructing what we know and understand about particular experiences or phenomena.

Foucault (1982) also highlights language and its connection to power. This also is reflected in my own quest to position myself as a researcher as I am privy to the current thinking and discourse about how we define the world for someone with a learning disability and or a mental health issue. I would want to be conscious of this and the importance of this in defining what we know or think we know about people with learning disabilities and to challenge this where necessary if this is not representative of gender or the individual experience by enabling those who cannot contribute easily to this discourse to be able to say what they think and feel about something importance to their experiences of care and treatment. It is then a challenge to interpret this in a way that is conscious of current social and contextual elements. This brings us back to the idea of reflexivity and positionality advocated by Holmes (2020).

### 1.3.2 Epistemology

The statement relating to my ontological positioning above that reads "...experience is unique and meaningful in order to construct meaning for that individual" leads me clearly into my epistemological discussion and way in which I see the perception and acquisition of knowledge. Epistemology has been defined in terms of exploring the potentiality of the knowledge in a human being (Bryant, 2000lt is concerned with how we acquire knowledge and through research how we epistemologically position ourselves as the researcher conditions by which means we generate meaningful knowledge in accordance with our ontology. By positioning myself more within a constructionist approach and the general acknowledgement of an ability to really know or understand another's experience is key to understanding the experience of the women I will be researching. If they are from a different group within society then it is important that I am therefore able to gain as much of their experience and then to adopt methods which would then allow that person's experience to be reflected back and interpreted within the appropriate research framework. How we know, therefore becomes about making sense by whichever means is most appropriate of something that we as a researcher will never experience and of presenting a world which we will never inhabit.

The positioning both personally and professionally outlined within my ontological discussion highlights the importance I place on previous education, knowledge and practices in order to be able to understand and therefore generate alternative or supporting perceptions / theories of particular groups in society. Burr's views on social constructionism also mean that we cannot ignore an alternative reality which individual groups inhabit, regardless or not of their own unique experiences

that may be fluid and ever-changing depending on current policy drivers, additional knowledge and trends (Garland-Thomson, 2006). By embracing this stance and then refocusing this on research, it is therefore inevitable that my epistemological positioning will mean that I aim to take an individual approach that also allows me to reflect and consider a group dynamic and culture. Because of the research aims, quantitative data is unable to provide me with the answers to my research question.

Hughes (2002) then brings this view of what knowledge might look like when there is even resistance to it, ie the person being involved as a participant may have a different standpoint than the researcher which means that "notions of truth" (2002: 153) then become what is known as reality depending on the telling of the experience and the story. Placing myself more towards a constructionist standpoint as already discussed can be problematic in that it means that by viewing each person's experience as a truth or reality means that it may be more of a challenge to initiate change then based on any generalisations made (Simons, 2009). While this one argument it is precisely this approach which can support a change in discourse and therefore challenge the social construction when presented through a new lens (Burr, 2006). Hughes relates her discussion around epistemological positioning and the acquisition of knowledge means that choosing a framework by which I can then draw new meaning from experiences related is crucial to generating meaningful data. It is important that the framework I chose, which is one pertaining to feminist standpoint and maintaining a fairly relativist position allowed me to stay focused on the requirement of anticipating at least some meaningful data and therefore a positive change from the study I conducted.

To continue and conclude this section on my epistemological positioning I will discuss the influence of Foucault and linking this to previous mention of the importance of social constructs on my ontological discussion. The mention of constructing reality and knowledge, referencing Vivien Burr (2006) previously is also reflective of the Foucaldian argument that discourse is not built around the individual but can be reflective of institutions, traditions and previous history within culture. Foucault argued that 'truth is linked in a circular fashion with systems of power which produce and sustain it, and to effects of power which it induces and which extend it' (1980: 133). Moving this into a feminist paradigm which I have chosen to frame my research study is fairly seamless as the central concept of feminist epistemology is of situated knowledge: knowledge that reflects the particular perspectives of the knower and has power and systems of power at its core. Therefore, along with the ontological position I have identified as holding means that the systems and cultures within the world of learning disability nursing, secure hospital care and the policies that surround those will undoubtedly influence the story that these women will tell. It is therefore my role to

disentangle their individual perspectives from those held by the institutions they reside in as well as to acknowledge the relationship between the two. Buker (1990) mentions that what Foucault shares with feminists and feminist discourse is a shared analysis of power and discourse around power. She comments that "He shares with feminists an intense and critical gaze at sexuality and power" (Buker, 1990: 231)

# 1.4 Introduction to a feminist paradigm

Feminist research has a history and a timeline. Some of those key points and links will be mentioned within this introduction to my research framework and can also be seen rather simply within the principles outlined below. Feminist research approaches are associated with some key perspectives, concepts and methodological approaches that will be applied to this study.

One key element that emerges from reading around feminist research approaches is that there is no one, definitive feminist method or methodology (Hussain & Asad, 2012; Gatenby & Humphries, 2000). Approaches to definition of what constitutes feminist research itself has been debated and defined over the decades with changing approaches as society itself changes and moves on and further consideration has been given to the lives of women and equality more generally (Harding, 1987; Im, 2010). However, there have been different attempts to provide a framework or a checklist of key features that should drive feminist research, whatever the methodological approach or methods employed to conduct the research study itself (Reinharz, 1992)

Below I have set out the elements of a feminist framework that will then guide and be used throughout the study and my writing to overarch the literature, the methodology, data collection, analysis and ultimately the conclusions that I will draw at the end. First of all I will outline the key features that drive and define feminist research or / and a feminist paradigm within which to construct and conduct research but then will also briefly discuss some of the elements or tools used to do this. Some of these may also be reflective of other approaches to research, particularly if part of the same general set of research methodologies (Archer, 2004) but I will link these to the concept of feminism and therefore my own study.

Hussain and Asad (2012) set out the feminist research principles below:

- 1. Focus on gender
- 2. The validity of personal experience against scientific method based largely around historical patriarchal research approaches that have not yet captured the experiences of women

- 3. Rejecting hierarchy in a research relationship and focus around power dynamics with particular emphasis on the female experience
- 4. Goal of the research should be to enable change, both socially and politically

"Feminist research is concerned with studying the issues facing women at its starting point. It seeks to search and explore the social dynamics and relationships in patriarchal society from women's perspective. Feminist research is not just adding women to the research equation or engaging women as researchers. Feminist research takes into account women's viewpoint as the base of the research."(2012: 203) This can support with bringing about and promoting change as we begin to see different issues and systems from a unique and different point of view. The challenge is then to be able to disseminate this information to those that are willing to listen and ensure that these perspectives are then considered when planning care and treatment and developing services.

It is important that each of the above points are seen through the lens of feminism, namely the desire to change things to make things more equal between the genders in society. As feminism has evolved along with feminist research this is not always now exclusively about women but continues to be driven by the lives of women (Levine, 2018).

The focus on gender appears self-explanatory and I have chosen this particular terminology to outline feminism and my framework for research due to the word "gender" and not women. Personal experience and evidence against the scientific method is belying of the emerging belief that objectivity and the hierarchy of scientific evidence is rooted in patriarchy and male experience and therefore calls on the adoption of other approaches to provide value to the data we may have through other approaches. There are those who argue that rejection of the scientific method is short sighted (Hammersley, 1992) but many feminists would argue that alternative, experience based approaches are necessary to provide the real picture and clarity to data which may ignore contextual information. That is not to say that all feminist research uses qualitative methods but it is certainly more likely to be the case. Rejecting hierarchy allows for the researcher to reject traditional, perhaps perceived patriarchal approaches to gather data and to enrich the data by allowing the participant more involvement. The task therefore is to work out how this approach to research becomes robust and allow for findings that can be used to effect change in a meaningful way. The final point around the goal of the research reflects the need that feminists have had to effect change, often of a political and social nature in order to improve lives of women rather than to simply present data to no further end.

I have then taken these principles or features of feminist research and condensed them into a framework that will guide my work and discussion going forward. It is notable that other theoretical frameworks or paradigms including those under the umbrella of humanism and person-centred approaches also embrace a number of these principles. The focus on gender and the desire to look at the world and this research question through that particular lens in order to generate further knowledge is what separates the feminist framework from others.

Guiding feminist research principles for my study

- The relationship between the researcher and the participants. Ensuring there is respect, something reciprocal and not being afraid to share something of myself in order to enrich the data collection process.
- The focus on gender and its social construct within a disability and political context
- The desire to change and influence the care landscape for women within these services.

The next sections will now explore the research within a feminist framework, based on the principles outlined above. This will then allow me to take the reader on the journey from positionality, adoption of the feminist framework to reflect this and then into the chosen methodologies that will be discussed within Chapter 3

# 1.4.1 Rejection of the hierarchy and the research relationship

Stanley and Wise (1990) are frequently referenced within the post-modern / post-positivist wave of feminist research and put great emphasis upon the importance of reflexivity, the researcher / participant relationship and language within feminist research. They also discuss in their work the importance of acknowledging and even attempting to address or redress the balance of power in some way. They are credited with helping to develop feminist standpoint theory which advocates and aims to understand the world and acknowledge the views of those within different social groups. Stacey (1997) builds on the idea of feminist theory by referring to it as "umbrella" in nature and able to shift according to the needs of the researcher and her participants. Many more recent references appear to embrace this particular facet of feminist research with statements such as "Implicit in feminist research is the attention given to power..." (McAndrew & Warne, 2005). This power appears to be multi-faceted, not only encouraging the researcher to empower those they

research, but also the use of reflection in order to think about the potential power of the researcher themselves and any possible hierarchical conflict (Burgess-Proctor, 2015).

Robson (2002) quite nicely describes feminist research as essentially "emancipatory" research and that it can therefore be seen as forming part of a number of different research approaches or paradigms which aim to give "voice" to their participants. Smith (2008) echoes this in saying that feminist research essentially is a "quest for voice" (p.23). Smith also refers to feminism as seizing the high epistemological ground in doing this so that seeking to empower the participant through its acknowledgement of gender and inequality at its root is essentially the root of feminist research. A similar ethos is also apparent in social disability research frameworks, such as Goodley (2016) who makes reference to research being participatory or emancipatory. Both approaches aim to include the participant within the research process and that will allow the data to be more valid and rich.

In order to construct meaning within the narrative of the women I have chosen to research it is important therefore to adopt a theoretical position that allows me to consider all of their needs, clinical presentation and be able to reflect on the way in which I am carrying out and then analysing and presenting their narrative. Referring back here to my previously outlined epistemological position and acknowledgement of myself and my own knowledge within the context of this research study, feminist focussed paradigms are able to highlight this in terms of lending the researcher position and knowledge to the research process in a positive way. Adopting a feminist position and attempting to include the women more equally within the research process was important. I had to essentially reject some of the traditional hierarchy of evidence that warrants detachment and objectivity on the part of the researcher (Aveyard, 2014) to allow this to occur.

Clarke (cited in Oakley, 1998) does however offer a slight counter argument to taking what could simply be described as a second wave approach to feminist research which resonates with my study. That argument is that some groups of women or even individuals do not quite fit into the feminist aim and idea. Concepts such as liberation, emancipation and rights are perhaps important to the researcher and even to society's construct of vulnerable groups (Garland-Thomson, 2010). However, they may not hold much importance for the participants themselves, knowing what we know about their backgrounds, understanding and acceptance of the world and hopes for their future. From this perspective feminist standpoint theory does not quite hold up in its original aim. Essentially, what women with learning disabilities in society have in common is a lack of freedom, a history of trauma and abuse which they may see as deserved (Aiyegbusi, 2002) and a fear of confronting these. It is important therefore to focus on using epistemology and therefore the chosen research paradigm in order to acknowledge and remember this.

What feminism as an approach does do to address this concept is to offer the researcher the opportunity to be reflexive in their writing and to always consider their interpretations of what they are hearing and reading about so that they might be able to present a more careful ontological and epistemological approach. Feminist researchers must seek to represent their participants as far as possible and use the tools at their disposal to do this (Van Stapele, 2013). Hughes (2002) exploring feminist theory and research links this to feminist standpoint and the dilemma that feminist researchers may face when positioning themselves ontologically. What Hughes explores, citing writers such as Oakley (1998) is that while all feminist approach has key principles at its core, that the route to knowing, if located in the participant will then mean that interpretation will inevitably take into account knowledge that creates a reality and a truth that is unique to those involved in the research at the time.

Feminist research more recently following on from the 1990s and beyond has begun to identify that while feminist methodologies as unique methodologies can sometimes be difficult to define, particularly when researchers may take such different standpoints between positivism and realism or relativism then it is therefore important to find that common ground in feminist research that at least provides an overarching paradigm with key aims and beliefs.

Many writers discuss the concept of power and politics within feminist research. Griffiths (1995) refers to feminist analyses as acknowledgement of positions of being devalued, experiences of being silenced or even openly oppressed. So while I rely on my own ontological and epistemological positioning or standpoint to influence my ability to conceptualise and present experience, the empowerment stance I take is very much a feature of feminist research in line with my own values as a learning disability nurse. Feminist research, being very much mindful of hierarchies and also of power and authorities within the research process must therefore also include these elements within any review or analysis while also seeking to exclude hierarchical influence across the research process in order to attempt to produce a new way of knowing.

# 1.4.2 Feminist research and learning disability

It seems that whatever the chosen method for actually collecting data and even then analysing data, feminist researchers can also allow themselves to more carefully interpret the words and experiences of these individuals or groups with the focus on the unique experiences of participants aligned more carefully to their gender. (Van Stapele, 2013). In the 1990s there was work published

around feminism and the need to adopt a social model of research, particularly with regard to acknowledging the human rights and the "emancipation" of those with disability (Oliver, 1992). This also included those who may have traditionally been subject to more medical, quantitative methods of research and Mercer (2002) discusses social research models as being able to challenge hierarchies of power. This very much fits with and echoes more current feminist perspectives and research frameworks and lead on to more appropriate approaches to research data collection being adopted in order to capture individual experience.

However, Oliver's definition of emancipatory research is essentially research which would be carried out by disabled people and aimed at challenging oppression experienced in their everyday lives. Barnes (2003) describes the key characteristics of emancipatory disability research: accountability to disabled people, observance of the role of the social model of disability, empowerment of disabled people, and importance of dissemination and outcomes. He tells us that emancipatory research is about commitment and researchers putting their knowledge and skills at the disposal of disabled people and their organisations. This is something that Mercer described as a 'partisan' research approach which rejects the traditional research hierarchy (Mercer, 2002). This idea of rejecting the traditional hierarchy is found within feminist research discussion generally, yet Oliver (1992) and then others such as Zarb (1992) begin to discuss that true emancipation through research and by definition, empowerment is only possible within a particular disabled community when those being researched are active in driving and "doing" the research themselves. This is perhaps a little bit of an overstretch for my research which is heavily reliant on issues of governance and organisational policy. However, Mercer would suggest that his "partisan" approach is a start as "the reasons why local and national policy makers accept, ignore or reject research findings and recommendations are diverse and rarely within the control of the researchers, let alone participants' (Mercer, 2002: p.236). Mercer's suggestion of the partisan approach aims to include and empower as far as it possibly can while taking account of any potential barriers that may also be aimed at safeguarding individuals. An epistemological approach which allows me to take into account the services that the women are cared for within, the knowledge I have of the women and their clinical presentation is important to consider in order to enable the women to provide meaningful information that can be presented at a local level at the very least.

This fits beautifully into the idea that at its heart all feminist research approaches aim to breakdown systemic power imbalance which traditionally has gender at its core but also that it is "spiral" in terms of its aim to grow new knowledge and effect change over time (Griffiths, 1995: 155). Lloyd (2001) supports this leaning towards adopting feminist perspectives and models when researching

the lives of disabled women as she claims that "the problems experienced by disabled women can be seen to be as much on account of their gender as their disability" (2001: p.716).

Walmsley and Johnson (2003) state that "...disability studies and feminism have passed through the stage where narrating pain and oppression is what it is all about. However, just because others have done so does not necessarily mean that learning disability research will follow the pattern. Learning disabled people can contribute in many ways to research on situations where they possess unique and valuable experience (Goodley, 2017). But to argue that they have the expertise to carry out or control all aspects of research is to go beyond the realms of the rational into a world where the reality of intellectual impairment is wished away and difference is denied" (Walmsley & Johnson, 2003: p187) Walmsley and Johnson show how successful contribution is possible in their book *Inclusive Research with People with Learning Disabilities*. Nevertheless, they also acknowledge the need to tailor research to the individual in order to make the research process valid.

This is an important implication for my research, showing the significance of following the principles of feminist research in research with learning disabled women in secure care. It is perhaps a little unrealistic to expect full participation of the women in every aspect of this study. This may be due to fluctuating health, limitations of conducting a study within a hospital setting and their varying levels of understanding and disability. However, an inclusive approach, guided very much by my own nursing background and principles associated with learning disability nursing (DoH, 2009) demonstrates knowledge around the subject area and participant group which links my epistemological position of researching a minority, often traumatised group of individuals (Long, 2012) to seeking to allow the women a voice within their narrative that is reflective of their situation in society.

Considering discussion put forward by Burr (2006) and reference to Foucault (1974) it feels important that there is acknowledgement of the power of current practices around control and the enforced treatment of mentally disordered offenders within our care systems in the UK and beyond. This concept will be discussed further within the literature review when look at the practices of seclusion more generally but also the services generally seen to support women with a learning disability and the clinical presentations and characteristics more often associated with this group. Therefore, with the feminist approach guiding data collection it is imperative that alternative discourse, or thought on the subject of the experience of seclusion be heard where it is spoken about. This can then be directly compared to the aforementioned literature review chapter.

The concept of Intersectional feminism also appears relevant in offering a viewpoint or "lens" from which to effectively match up various aspects of participants' lives which together affect their

position and difficulties within society. <u>Kimberlé Crenshaw</u>, an American law professor who coined the term in 1989 explained Intersectional feminism as, "a prism for seeing the way in which various forms of inequality often operate together and exacerbate each other," in a recent interview with Time magazine in 2020. Concurrent forms of oppression within society therefore need to be considered when presenting and researching the lives of women with a learning disability who also have multiple diagnoses and "labels" that then go on to require treatment within the Mental Health Act (2007).

# 1.4.3. Framing my study

More recent writings around adopting a feminist perspective within research and its epistemology have moved on simply from acknowledging it as a way of critically approaching and reflecting on the female experience (Webb, 1993). Earlier influential writings of Oakley (1981) and Reinharz (1983) certainly struck a chord as they outwardly reject the traditional way of research which Oakley in particular argues treats its subjects as objects rather than participants in their own experiences. Reinharz is well known for the giving of voice to "hitherto silenced groups" (1983; p.462). However, while Oakley cites feminist research as being very much a dialogue which actively involves the researcher, there appears to be some lack of reflexivity when tackling the interpretation and actual involvement of the researcher and their own experiences. Essentially for the purpose of my own research, feminism represents a flexible way of working which also allows the researcher to reflect upon any ethical issues that may occur while continuing to discover a different truth (Foucault, 1988).

My perspectives and approach to feminist research in this study have been influenced by others' accounts of adopting feminist research approaches and methodologies, representing my own epistemological and ontological position. McAndrew & Warne (2005) for example, use Case Study as a methodology using a feminist perspective as outlined previously in this chapter to guide and interpret their work. They allow the feminist praxis to guide "gendered interpretation" (2005; p.174) of the experiences of the women that they interview. In 2010, Im conducted a systematic review of feminist research in nursing. While an American paper, Im cannot restrict herself to US literature, showing the limited pool from which feminist nursing studies can be drawn from. It provides a glimpse into the importance of case studies in order to guide ethical feminist principles and approaches from which I might begin my own study. I have also begun to try and relate this back to the literature around females and secure services and also my own experiences relating to women within secure care as a learning disability nurse.

It appears that feminism as an approach and particularly with regards to its value base (Webb, 1993) has distinct parallels with discussion and debate around disability (e.g social vs. medical). In 1999, Thomas asked, 'What would be the consequence if the feminist position that all knowledge is 'situated' were taken seriously in Disability Studies?'(p.81). This surely alludes to the importance of not simply concentrating on social and or even medical processes to define and discuss impairment or disability but the need to include the personal and individual experience of disability. This is clearly in line with the feminist approach, particularly those approaches considered from the 1990s onwards (Reinharz; Oakley; Harding). Harding in particular aligns herself often with post-positivism which allows a plural approach to methodology to be taken if felt epistemologically appropriate in order to gain a more critical reality of the subject matter (1986). It was felt for this study, due to the desire to try and understand how the participants themselves viewed their world, that a more qualitative, interpretative approach should be taken.

Klein (1983) emphasises the importance of "intersubjectivity" and interaction within the feminist approach to research. The article discusses the importance of the researcher and participant relationship and that by approaching the research study in this way would then allow for that narrative to be presented to others as a means of facilitating social change (Klein, 1983). Feminist research allows for their situation as women to be accounted for, for a drive towards social change to be considered, but also for the relationship between the researcher and participant to be made important within the data collection and analysis points of the study.

What I believe is that a feminist approach certainly would not dictate the exact way in which I conducted the study. While likely to be qualitative, there is still an ongoing debate as to what, if anything, constitutes the feminist method (Im, 2010). Im comments upon this when she discusses diverse epistemological stances that feminist researchers may take (2010). Simply by adopting post-modern or post-positivist approaches can alter the method by which data might be gathered. My epistemological position and outlining my own role as researcher was important to move forward. I was able to stay focused on what I knew already about the world inhabited by these participants and therefore use appropriate methods of data collection and analysis in order to present and interpret their stories. Feminist perspective allows me to seek to find their voice, review and interpret findings in a way that represents them and hopefully to look to make positive future changes with their guidance and involvement.

## 1.4.4 The role of reflexivity to demonstrate a feminist approach

Reflexivity and reflexive writing within the research process is one of the key underpinning elements that can help to define feminism in research and more accurately, feminist research. Reflexivity within feminist research is integral to the concept of the collaborative nature of the research between researcher and participants. Rather than concealing the involvement and personal viewpoints of the researcher it seeks to highlight the role of the researcher and their own engagement in the process. Reflexivity enables any concern around this to be considered carefully while continuing to embrace the importance of the researcher's own interest in the area (Oakley, 1981). This section will give a little bit more information about this and how I intend to use and incorporate reflexivity within my own research in order to achieve the best possible results, and by that I also mean the most authentic results. This section will look at how reflexivity formed a basis for choosing my methodological approach to fit the feminist approach I have chosen to adopt in order to understand the experiences of the women I will be researching. As Hammersley and Atkinson (2007) put it, 'The search for universal laws is downplayed in favour of detailed accounts of the concrete experience of life within a particular culture and of the beliefs and social rules that are used as resources within it' (Hammersley and Atkinson, 2007:9). A robust qualitative approach supported by this key tool within feminist research among others could succeed in effectively giving these women their voice, wrapped within concepts such as the reflexive, participating researcher.

A study by Brenda Downing in 2015 led to her publishing around her use of reflexive writing and embedding this to such a degree that she felt she was essentially "writing into knowing" (Downing, 2015). Downing discusses how her continuous reflection during the course of her research study was what allowed her to really demonstrate her paradigm and her methodology presenting her findings and more importantly, the way in which she then went on to conduct her research throughout. Feminist writers argue that good reflexive writing in research can in fact support that leap towards knowing and therefore interpreting and applying (Spry, 2009). Feminist research also has at its core the desire to facilitate positive change for those who are traditionally ignored or left out of research and these studies highlight how reflexivity can also go some way to enabling this. Within this chapter I will set out the methodological framework and methods that I will be using to answer my research question but will also include the way in which I will incorporate reflexivity into the research process.

Returning to other literature such as Van Stapele (2014) has also guided the way in which I use a feminist approach through reflexivity and also the researcher / participant relationship to gather, interpret and then use my data. This will be demonstrated through examples of reflective writing as I explain further on how this study will be conducted. Undurraga and Sang's 2012 study called for an

interactive research process and this more up to date study and discussion round feminist methodology brings to the fore early 1990s writing (e.g. Stanley and Wise and Reinharz) where the idea of bringing something of yourself as researcher and a degree of reciprocity is key in obtaining rich and robust qualitative data. Undurraga and Sang (2012) who were looking at Chilean women and their experiences allowed for their own background and experience to epistemologically and ontologically guide the approach but then also support with allowing the "subjects" voices to be heard through the use of reflexivity. They tried to break her outsider position by becoming an important part of the research and the data analysis process. This is key in feminist research and also allows the feminist researcher to consider the potential juxtaposition or "double consciousness" (Stanley and Wise, 1983) of partially understanding the position of your participants because of your own background but then also recognising your own interpretations within the presentation of data and the need to counter this at times. This is in part why a feminist approach in terms of breaking down hierarchical structures, interaction between participants and allowing my own background and influences to guide my own study is so important. Self-reflexivity as a core principle of a feminist paradigm will also allow me to robustly present the data as I take all of these factors into account during the analysis stage.

I wrote one phrase in my early reading time which outlined what I wanted my research to achieve...

"I want to empower my research participants. I want them to feel that they can discuss their experiences with me and not simply say what they think they ought to. These women have not had the level of focus that they deserve within care services dedicated to nursing them and also by society."

This, I consider as reflexive as it was written following an intensive period of reading around epistemology, feminist approaches and also female services and restrictive practices within learning disability and mental health settings. Van Stapele (2013) highlights for me the importance of this type of reflexive statement as it not simply enough to be "person-centred" (DoH, 2001) towards the vulnerable and oppressed individual with a disability, but that it is this self-reflexivity which brings about good analysis following on from data collection within the research process. When considering methodological approaches and methodologies, inclusive of Interpretative Phenomenological Analysis (IPA) and Case Study, I wrote that I instinctively knew that what I was doing was using my nursing in order to support the women and my data collection through the research process but that this was definitely more than just a nursing approach. I began then at this point to go back to the literature pertaining more specifically to trauma, abuse and what it was to be female within such services. How would I approach these topics with the women when necessary

without simply reproducing what we already know of even reinforcing stereotypes as demonstrated in literature? What a feminist approach and the incorporation of reflexivity within that could potentially do was to offer an interpretative power and allow a narrative that are not merely observations.

This argument for using reflexivity as an analytic device is supported by publications such as Van Stapele 2013. This piece of writing was important to me when looking at how I was able to really find the right methodology and way of going about approaching this study. Van Stapele, in her overall discussion around feminism and feminist methodology made one statement that I was able to really identify with. She said "I want to empower my research participants by revaluing their perspective, perspectives that have been hitherto ignored both in the academic world and in the world of politics" (2013: 16). I cannot say whether I wrote my statement above before or after I read this article, although I suspect it was afterwards and I took this example to form my own and to really support my choice of the feminist approach. This is the importance of feminist research as well as the way in which the participants can be empowered during the research process...what happens afterwards? How do our words change things for these individuals for the better? Isn't that what we should be aiming for?

And so Van Stapele, like other more generic feminist writing, advocates for the use of reflexivity by the researcher. Reflexive approaches she argues also allow us to think about our studies as being almost anthropological in nature and allowing the participants themselves to begin to reflect differently on their experiences. Obviously, by beginning to analyse my own language and questioning style should hopefully allow for this to happen a little bit, although there have been definite limitations around this in relation to my own study, not least my own inexperience as a researcher but the intention is certainly there.

## 1.4.5 Strengths and limitations of the feminist approach

This section summarises the feminist paradigm that has guided the methodological approach to the study and shown within the next chapters and then into results and discussion in the second half of the thesis. Strengths and limitations that demonstrate it is the right approach for exploring the lives of these women from this perspective are highlighted.

#### Strengths

# Empowerment

Finding that voice in a group of individuals often previously ignored and allowing them to tell their narrative. However, as feminism also seeks to promote some kind of change for better then there are some thoughts around feminism and feminist theory which as an overarching framework have then allowed me to go on to develop and acknowledge my data collection methods and approaches to analysis which aim to support this more. At its core feminist research in terms of its aim and methodologies focuses on emancipation. This is also representative of my own positionality as a learning disability nurse, an individual as well as a researcher. A consideration of the history of female secure services still serves to highlight the importance of the concept of empowerment and emancipation for these individuals who in fact deviate from many traditional gender constructs and will be examined in a little more detail with the literature review section and then explored more deeply within the final discussion of this thesis.

# Reflexivity

I have discussed the role and importance of reflexive writing and conducting reflective discussion within the context of feminist research earlier in this chapter. Within the methodology chapter I will take a closer look at my methodology and methods I will use to gather my data and hopefully generate further understanding of the experience of my participants. I will be able to show the reader through the methodological discussion and then my findings that reflexivity, considered as part of a feminist approach will strengthen the data analysis and, considering literature and interpretation from the gendered perspective and the lives and histories of these women.

# **Limitations**

Applying social construct theory and considering the cultural context of the participants within my study is to selectively consider the emergence of services for women with a learning disability historically. This means that key to understanding the female population as a whole means that we consider the importance placed upon the ethos and treatment approaches to the male service. We can show that women's services have only recently begun to adopt my unique approaches to care in line with the individuals that they are nursing and that research has begun to show differences in clinical presentation and efficacy of treatment approach. It is important therefore that a feminist lens be applied to the literature, able to point out whether nuances are in fact based up on predetermined social construct, e.g. the leaning towards certain diagnoses for men and women who present clinically similar. Do our pre-conceived constructs of gender mean we then pre-determine the different approaches that we take. I believe that this is important to offer a unique and different

way of exploring the lives of these particular groups of individuals, however, there may be a risk that by concentrating so much on systems and constructs that we also in fact miss the individual experiences of the individual participants themselves who may not easily be separated from their cultural environments. However, there are aspects of the feminist paradigm which could counter this. Ensuring that a person-centred ethos as outlined within my own ontological discussion earlier means that each person's story will be gathered in a way that allows them time and space to answer the questions I have for them. I will discuss this in more detail within my methodology chapter and plans for data collection. However, I think what is also important to acknowledge within my own feminist framework is that while I intend to adopt a number of key principles embraced by feminist theory and research approaches, acknowledging the need for the lives of women with learning disabilities in secure care to be discussed more carefully and in more detail, I also wish to use some of these principles to counter any potential difficulties with methodological standpoints. Using ontological and epistemological standpoints aimed at improving the lives of people with a learning disability and valuing cultural and group experiences in shaping new ideas I also aim to counter the idea that this is all about gender and that these women believe that they inhabit the world that we think they do.

# 1.5 Chapter Summary

The chapter has set out the research aims and objectives, the overview of how the thesis will be constructed and then focused on the positionality of the researcher to then explore the way in which I can begin to frame the study so that the voices of women with a learning disability in secure care and their experiences of seclusion can be captured in the best way to present new knowledge that is representative of them. I have discussed the background of women with learning disabilities and secure services to introduce the topic but this will now be explored in depth within the literature review, using the feminist paradigm I have described to frame this. I have then gone on to define my ontological and epistemological positioning within the discussion around discourse, power and social constructionist theory which has then led me on to adopting a feminist paradigm within which to capture the ethos and value within this research study. It is important to remain true to my positioning and values and the way in which I believe valuable knowledge and truth can be produced and represented within a unique group in society. This will allow me to better define an appropriate methodological framework and to then present this while continuing to acknowledge the feminist principles outlined within this chapter. This study is about women, it is about underrepresented

women and it acknowledges the role that our pre-defined institutional structures govern the way in which we capture experiences to date. **Chapter 2: Literature Review** 

# **2.1** Brief introduction to the literature review

My introductory chapter outlined the framework within which I was setting out my research and the rationale for the choice of using a feminist paradigm, incorporating a feminist lens from which to explore the use of seclusion and the experiences of women with learning disabilities in secure care

within the UK. This introductory section has allowed me to explore my epistemological and ontological position as a researcher and thus identify and establish a suitable framework in order to conduct a robust research study. It is therefore important that I continue my thesis using the feminist framework and that continues to important within the literature review. A reminder of that feminist framework is shown just below but what this chapter will do is present relevant literature to the research question, demonstrate how this literature was used and appraised to produce a more comprehensive picture of the experiences of seclusion in relation to the lives of women with a learning disability.

## 2.2 Framing the literature review and models used

A reminder of the framework chosen is set out briefly below in the table and the guiding principles and literature that have shaped its development.

- The role of reflexivity
- The relationship between the researcher and the participants
- The focus on gender and its social construct within a disability and political context
- The desire to change and influence the care landscape for women within these services.

What I endeavoured to do was apply this framework to every aspect of my study and the literature review is no exception. The review will appraise the literature and then link back to the feminist framework, with its focus on gender, social construct and the political climate within which it was written and published. The literature needs to be interpreted to reflect the feminist perspective that I am taking towards my own research study so that I can begin to draw on previous learning within the context of the female service user. Once again, a feminist framework adopted and applied across all aspects of the research process will support and guide me in the choice of literature. This will then further support choice of methodologies, data collection methods and analysis techniques.

The literature presented provides a range of background reading which then guided further literature searches and comparisons. However, considering epistemology, ontology and research paradigms first allowed for me to ensure that the literature chosen would then inform the way in which I chose to carry out my research study and the questions that I would ask the women about their experiences of the seclusion room.

Within each section I intend to consider the principles outlined in the list above and to ensure that this is clearly demonstrated throughout the review. This does mean that different viewpoints can be carefully considered allowing for reflexive consideration. It also means that gender and its social and

political context will be thought about as we discuss the chosen literature and will hopefully allow the reader to see why literature presented within this review is the most relevant and important to shaping this study. Im (2010) stated that "...feminist nurse researchers should analyse traditional research and research methods so that bias based on gender, race, class, sexuality, or disabling condition can be avoided." (2010: 23)

I am going to demonstrate the inclusion criteria for literature based upon my chosen framework and the guiding influence of supporting concepts and frameworks already discussed, such as feminist discourse and social construction (Burr, 1996). For example, literature may stand alone meaning that the study does not reflect the topic I am aiming to research or the participant group. It may be a study that stands apart from other similar studies in its area due to its qualitative methodology or lesser known authors. It may adopt similar methods that my own study goes on to adopt, namely the single or multiple case study. My reasons for using studies will be carefully shown to align with my chosen overarching feminist framework as outlined previously and above. Studies therefore will be not only selected from within the UK but this reason will be explained fully within the section concentrating on the topic of seclusion itself which demands a wider global and political exploration as well as ensuring that some literature roots such concepts more firmly within our UK healthcare system and the legal framework of the Mental Health Act 1983.

Equally when considering the treatment and management of women within secure care settings, whether the UK or otherwise, the feminist lens is crucial to robust and careful use of the information being presented. Gender studies concerning issues such as self-harm, levels of violence and aggression and subsequent management of both are often comparative in nature and gender is considered solely in terms of how women and men fit differently into the secure care setting and what it is able to offer both. While this kind of study is often influential in highlighting the need for change or identifying particular therapeutic challenges it is the feminist lens adopted here which will allow me to consider the quality of such research, and its relevance to my own study. By considering the approaches used from a feminist perspective, it should allow me to generate further questions. I have chosen to highlight this so that the reader can understand how the feminist lens will shape the literature review.

# 2.3 Finding the literature

#### 2.3.1 Information sources

Interestingly, when considering relevant literature and literature searching relating to my topic and the types of evidence that are required it is necessary to reject the traditional hierarchy of evidence. This is interesting simply because a rejection of the hierarchy appears to mirror the rejection of hierarchy and patriarchy that will be considered within my own literature review as I aim to consider existing evidence and research through the lens of feminism.

Aveyard (2014) reflects on a hierarchy of evidence for qualitative research or for a systematic review and states that "your own hierarchy of evidence is based on the evidence you need to address your particular question" (Aveyard, 2014: p.68). It is important therefore that we do not revere the traditional hierarchy that highlights the Randomised Controlled Trial (RCT) as well as other quantitative methods so that qualitative literature is seen as more second rate but justify the need to develop a hierarchy and therefore search criteria that really fits the question I am asking which is essentially relating to the experiences of individuals and the secure care context that they occupy.

My hierarchy of evidence began to form as outlined below:

- Primary research relating to the research topics and / or encompassing similar research methods. Qualitative research incorporating patient perspectives should be prioritised.
- Systematic literature reviews of the use of seclusion and services for women with a learning disability that include seclusion perceptions and / or experiences.
- Key policy and expert opinion regarding the use of seclusion and / or people with learning disabilities in secure hospital care.
- Primary research that adopts a mixed methods approach in order to show trends relating to the use of seclusion and / or people with learning disabilities.

Scoping reviews serve to synthesize evidence and assess the scope of literature on a topic. Among other objectives, scoping reviews help determine whether a systematic review of the literature is warranted (Trico, Lillie, et al. 2018).

This literature review is based upon a scoping review approach. Rationale for adopting this approach included a knowledge and discovery that little specific literature was available through traditional database searches (PubMed, MedLine and CINAHL) but also due to not being entirely sure what literature did in fact exist due to lack of focused studies in this area. A scoping review of the literature allowed for an organised and methodical mapping of literature in order to identify key

concepts from which to focus methodological design (Daudt et al. 2013). A scoping review also enables the researcher to identify gaps in literature or knowledge which can then go on to help inform practice. This was important for my study due to the feminist principles being applied to the study and that important emphasis on change.

To identify potentially relevant documents, the following databases were searched: CINAHL, PubMed, MEDLINE and ETHOS from the British Library and also ProQuest Dissertations and Theses. These choices allowed scoping of widely available literature but also helped to identify and find harder to reach literature.

Final search results were exported into EndNote. The reference lists of a selection of results frequently cited were scanned for any further results, particularly where methodological design and approach showed similarities to my study.

Articles and relevant chapters and books were identified through searching electronic databases and also hand searching of literature gleaned from initial and further reading, which within a scoping review is often recommended due to its suggested inclusion of grey data. Databases either yielded hundreds of general results that did not fit with the required study title although some useful for background reading and combining phrases to include gender and seclusion only yielded a handful of results from all three databases. Further searches were carried by conducting a combined database search. These databases were chosen because of their relevance to healthcare and nursing. Searches were conducted using the criteria set out below.

# 2.3.2 Inclusion and exclusion criteria

- Timeframe Up to date but also seminal. Up to date would depend on the nature of the literature. Anything regarding the process of seclusion and its relevant policy should post-date the amendments to the Mental Health Act (1983) in 2007. Literature regarding the care and treatment of women with learning disabilities in secure care can be earlier than this but influential policy should post-date the Reed Report (1992).
- Qualitative or mixed methods primary research. Additional data where evidence or findings
  will support other literature or findings from that literature. For example key government
  policy or law that impacts on service design and provision.
- English language but covering services globally that are broadly comparable in terms of the contribution to the therapeutic and elimination research and debate. These included the

UK, Finland, Netherlands, Australia, New Zealand and Canada. Similar socio-economic and demographic factors also contributed to such comparisons.

Search terms included gender; women; learning disabilities; intellectual disabilities; seclusion; restrictive practices; restraint; secure care; secure hospital; mental health care; female; experiences; forensic. Combinations of these terms were used and also separated when no literature was identified.

25 results in PubMed just from seclusion and intellectual disabilities which was reduced to just 3 when combined with terms including gender, women or female. Searches yielded a saturation across the databases quite quickly but adding additional databases enabled some further literature to be found and were synthesised to identified common literature within reference lists also.

Initial database searches were then supplemented by synthesis of frequently cited references including book chapters and further articles via additional databases such as ProQuest.

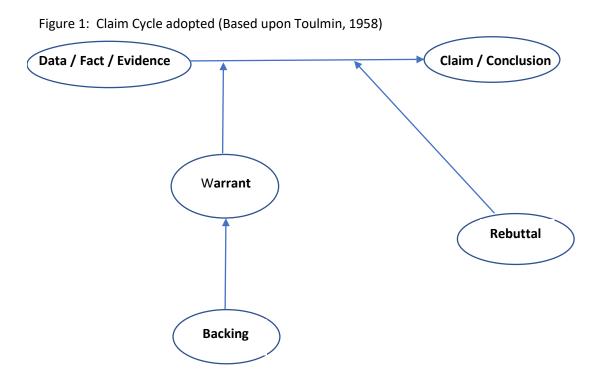
# 2.3.3 Claim credibility cycle

Given the topic being explored, it is highly likely that the selection of sources and the availability of literature fitting the research topic and question is quite limited. It is also likely that many primary research studies and also reviews of these studies as well as other secondary sources are highly influenced by the small pool of evidence also being discussed here within this study.

It is imperative, that as well as the guiding principles of the chosen feminist framework outlined above, the choice of literature and therefore the focus of the research aims and question can be justified and used effectively to help guide the way in which this study is carried out and to clearly show how research aims and methodological approaches were chosen.

This review will show the validity of chosen literature through acknowledgement and close alignment to a claim cycle (Toulmin, 1958). While Onwuegbuzie and Frels, in their "Seven steps to a comprehensive literature review" use this concept to design their claim credibility meta-framework tool (2016), it is the overarching principles outlined by Toulmin that I intend to use, which means exploring which claims are being made within the literature? Are they claiming to be factual, claims of observation and therefore what is the evidence and trustworthiness level supporting such claims? How do we reach particular conclusions about the need to include a particular piece of evidence or research and what supports the findings or review of this literature? Beginning to conduct a

literature review through a feminist lens means that feminist epistemology will be demonstrated through the use of this claim cycle.



2.4 Women with learning disabilities and secure care

There is a small but growing amount of literature that has explored the experiences of learning disabled women; however there has traditionally been very little research with women who live in residential or secure institutional type services (Allen et al., 2001; Hellenbach 2015). Some of the literature that will be reviewed as part of this chapter suggests that the reason for this is that learning disability services have traditionally hidden behind a 'gender blind' approach (see also Scior, 2003). Therefore to build up a more comprehensive picture of learning disabled women and their experiences of secure care services then we would certainly need to consider the wider literature that pertains to some of their lived experiences as outlined in this small repertoire that we have. Literature has been discovered and analysed using a comprehensive database search and a cyclical approach used (Onwuegbuzie and Frels, 2016) in order to ascertain the quality and to attempt to introduce new concepts from which to move forward within the field of knowledge. This approach as outlined in O & F also allows for reflexivity, staying close to the value and experience of the

researcher themselves. If learning disabled women in secure services have similar experiences and needs as women living in secure mental health services due to the services that they have been nursed and cared within (James & Warner, 2005), then what are the cross-cutting themes arising in research, inclusive of small scale studies and women's own testimonies? This chapter will consider these themes, as well as exploring specific concerns which arise in the literature about women in services, such as self-harm, trauma and abuse.

Some authors include women in residential services as research participants as well as women in the community (McCarthy, 1999; Scior, 2003), and others, including my own work within the UK, focus on women in secure services but explore only a particular aspect of their lives or of those caring for them (Duperouzel & Fish, 2008; Duperouzel & Fish, 2010; Fitzgerald & Withers, 2011; Goulding & Riordan, 2016 Harker-Longton & Fish, 2002; Sequeira & Halstead, 2001; Thomson & Johnson 2017). Perhaps due to the heterogeneity and medicalisation of the population of adults who have been labelled as learning disabled, research has concentrated on medical syndromes and service provision (Aspis, 2000) and has, with little exception, been presented in a gender-neutral way or focused on the disability aspects (Atkinson et al., 2000), with papers not specifying the sex of their participants or attempting to make direct comparisons between genders within a gender blind or neutral service (Scior, 2003; Emerson, 2001). As outlined in more recent studies there is a 'significant need for women with intellectual disabilities to be heard and ... the meaning that they ascribe to their lived experiences acknowledged' (Taggart et al, 2008: 205). Traustadottir and Johnson (2000) describe how it is particularly difficult when researching this group of women, not only because of the limited evidence and the tendency to ignore them within other feminist or disability discussions but the fact that research often tends to focus on a very small handful of subjective experiences which are often poorly presented due to difficulty in interpreting data. This can then potentially cause problems when trying to develop theory and ultimately care and treatment. It is therefore key that the literature reviewed will help develop an understanding of the research group, their clinical needs and the way in which this study should be approached.

It is clear that within UK secure services, whether learning disability services or not, women are in the minority. Byrt et al. (2001) discusses this fact however, there is little more recent evidence to dispute this (Beber, 2012; Hellenbach et al., 2015) although some services have now tailored towards providing unique services for women (Home Office 2007; Home Office, 2012). Hellenbach et al. (2015) conducted a search for relevant literature relating to this population group using a systematic database search and even though they had strict inclusion criteria based on the review

question, their searches yielded only four relevant articles. Key, but historic reports such as the Reed Report in 1992 highlight the recent difficulties that would have been experienced by women who had been diverted or placed into the secure system.

"In male dominated environments, women's needs including their more personal female needs are liable to be overlooked...Services need to be responsive and proactive in order to counteract these problems in order that women receive appropriate care, treatment, accommodation and rehabilitation with proper attention to their personal dignity."

(Department of Health and Home Office, 1992)

This was reiterated by Hassell and Bartlett (2001) almost a decade later who even suggest that women may continue to be subject to social contact with men within a secure service because of the way in which services are tailored towards the majority of their patients which are men. The knowledge we have about women within these services are that they have often been subject to sexual abuse, trauma and coercion by men in their pasts (Aiyegbusi, 2006). They scoped the distribution of women within services across the UK. This provides evidence within that historical, chronological context with regards to females and secure services. However, its findings support the claims that services were androcentric and therefore add credence to claims of services being unresponsive to female need but do not offer new insight into why this may be the case today. In 2007, Hayes continues this observation and wrote a literature review about women with a learning disability which discusses how services for women continue to be lacking, in so far as women tend to be placed further away from their home and family due to fewer services being available. She admits that services for women deemed to require secure care are still male dominated and male focussed and that further research needs to be done in order to inform policy changes and to add to the dearth of literature existing in this area.

Hayes echoes what Hassell and Bartlett had been saying six years earlier when they say that most of the literature pertaining to women tends to focus on the special hospitals at that point and therefore not representative of women within other lower secure services and the community (2001). Parry-Crooke (2000), writing for the WISH charity, while aimed at advocating and offering support to women in the high secure hospitals made inroads into offering up the "voice" of the women, they are certainly only a small sample of those women within the secure system. Hayes states that 'Female offenders are a small, neglected and devalued group within the criminal justice system; the even smaller minority group with a learning disability have little in the way of specific resources, services or advocacy' (Hayes, 2007, p.190). Hayes also discusses the relevance of her review in that it calls for further research into the lives of women with learning disabilities in secure

care and even suggests that their unique experiences need to be considered perhaps through life story narrative as an example. The claim within the Hayes article concerning women and the chances of them receiving less appropriate care and treatment than men is also key in developing the way in which this study might begin to consider the lives of women within the context of what care delivery has historically looked like for this population. In 2007 Baroness Corsten provided some context to this focus however when she echoed the previous findings of the Reed Report back in 1992 which discussed the lack of lower secure options for women traditionally, meaning that women were in fact often detained within settings with higher security levels than was perhaps required for an individual or group of women (Hayes, 2007).

Crawford (2001) interviewed ten women with mild or borderline learning disabilities and their care staff in two medium secure units in England. She reports that during admission 'all women had cut their bodies' (Crawford, 2001:6), and many had assaulted staff or other patients. Her interpretation was that the women used self-harm as a way to bring revenge upon their carers or to punish themselves. More commonly, however, women used self-harm as a way of releasing tension, a phenomenon also described in other more recent research (Fish & Duperouzel, 2008; Goulding & Riordan, 2016). Crawford describes the women as having developed a 'hierarchy' of self-harm which was directly linked then to the level of response this would elicit from staff. It was essentially a way of being seen within the service.

Crawford (2001) refers to the 'invisible gender' as representative of women in secure services, which allows the service to ignore any potential differences between services offered to men and women. However, what we see through this article and subsequent writings about women, in particular relating to their common diagnoses is that women then actually do become visible but not in the way that supports positive change or service provision. They become visible through their behaviour traits, again commonly associated and demonstrated through progress reporting and outlined within work around emotionally unstable personality disorders in particular (NICE, 2018). This quote from Crawford's article outlines this issue:

"The oppression of women as a visible gender allows for effective institutional functioning. Unsurprisingly, those who challenge the system are thought to be deviant and become a 'visible' hazard to the institution." (Crawford, 2001:156).

This issue of services having difficulty in acknowledging gender and gender identity is then talked about as existing within the group of women, rather than being situational (Aiyegbusi, 2004).

Aiyegbusi also mentions that this type of discourse or language used about a person can affect their care. Labels such as 'difficult' can be used by staff when talking about a person, and reinforced

through case notes and the "copy and paste" tendency over long periods of time (Johnson & Webb, 1995; Peter, 2000; Williams et al., 2001).

Crawford's observations of the invisible gender are likely to be interpretation and based upon policy that up until that point in 2001 had shaped the way in which services for women in secure services were delivered. She discussed some level of empirical data based upon her own small-scale study, however, this is then further supported by evidence from additional studies some years after. Women are no longer housed in wards that cater also for men, but they do still often represent the smaller number of wards within a larger hospital setting, also treating male offenders.

The Bradley report (2009) set its aim out as responding to what has commonly been termed "revolving door" issues for offenders identified as having an additional and pervasive mental health issues or a learning disability. The Bradley Report looked to set out a clear plan which among its aims was the reduction of ASBOs, reducing time within prison settings and enhancing the support offered to those with a mental health disorder and / or a learning disability within the criminal justice system. Despite this report being seen in 2009 as very much needed and integral to care going forward, women actually only receive scant mention as a group of individuals who perhaps need services to be different from those offered to men. What Bradley does do is ask for a more skilled workforce in order to support individuals around what the report considers as "gender focused" topics. These include for example, borderline personality disorder, self-harm and gender training in general. It is interesting however, that women are seen here as different in terms of the way they present in their behaviour and the challenges that that is seen to pose to services. This observation of this report which provided a landmark in care and treatment offered to offenders with a learning disability echoes what Crawford wrote eight years earlier. Crawford refers to the "invisible gender" within institutions and secure services. It is important to remember when Crawford was writing at the beginning of the 21st century but she certainly highlights how services did not always aim to recognise difference between men and women in terms of the services they would receive but that things became problematic within a female service due to the difficult behaviours that women might then display which is then linked to gender. However, Crawford presents these discussion points without any in depth discussion of her interviews. We are unable therefore to see where her interpretations actually come from.

Rebecca Fish (2018) has published a number of focussed pieces based largely upon her ethnographic doctoral study which took place in 2013 at one UK medium and low secure hospital site which in addition to male services, also provided care for female service users with a learning disability. Fish was able to comment upon the use of seclusion as one element (2018) but in addition, observed general life on the ward environment for these particular women. Fish's recent book based upon

her doctoral research is essentially an overview of her experiences researching with the women but is particularly interesting as her own interpretation mostly appears to mirror the interpretation of the women through the presentation of their own words. Although interviews with staff members are also presented as well in support of her writing.

Williams et al. (2018) published their paper around the subjective experiences of a group of women with intellectual disabilities within one hospital settings. Earlier, this review alluded to the fact that literature focusing on the phenomenon of women with LD / ID in secure care was always going to be limited due to the fact that only small groups of women at one time were being used within small research studies and it was therefore a case of bringing this information but focussing more carefully on the types of study and the way in which the women were seen as participants within the research rather than simply interpretation of findings. As mentioned above, Crawford's 2001 research makes some interesting points around gender and the differences in treatment approaches offered to men and women within services, however her lack of depth in her discussion does not show how she has really reached these conclusions or whether this is something we can apply to what we know about women with a learning disabilities and their experiences of being in secure care services. The Williams et al. (2018) study however begins to bring this depth through its more gender focused and exploration of the phenomena that is the female experience within hospital.

It is interesting that Williams et al. (2018) actually choose to use the title of "subjective experiences" which to some degree suggests that this study and its findings offer a more unique and important insight and can therefore be supportive to a wider population of women with secure learning disability services or even within community settings. The aims of the study would seem to embrace the use of the woman themselves as a robust source of data for the study. This is a more up to date endorsement of the Q-Methodology study by James and Warner (2005) who discuss the small scale study and its importance to not only adding to the wider literature, but also as representative of a social constructionist approach and how these studies often demonstrate the truth in how we have interpreted the political and historical context for women with learning disabilities (2005). The methodology outlined within the James and Warner study (2005) do not allude to the approach taken by the researcher other than the fact they used interviewing techniques and how these were facilitated within the hospital setting. The study does not appear to provide us with a particularly new or different focus on this population, and as already mentioned, it tends to be the "pulling together" of such studies, as up to date as possible that will provide the overview of female learning disability secure services and to see the approaches and direction that these services are taking. This can therefore be considered in recent policy context including the Transforming Care agenda (2015).

Theses aimed at exploring the views or experiences of women in secure care environments within the UK were also discovered. These theses, including Jones (2017) and Ridley (2020) served to support key concepts arising from a review of the published literature around women in secure care, those with learning disabilities and those without. Jones (2017) in her theses exploring the experiences of distress of women patients in a secure forensic environment in the UK highlighted the difference in perception between the patient and the staff nursing them of that distress with the women often citing sensory and physiological interpretation of their distress rather than it always being about their understanding of their emotions. In addition to this, Jones discusses how the women in her study feel misunderstood in their distress. This is an interesting study as it highlights the importance of communication and the inclusivity of the individual in their own risk management approaches.

Ratcliffe and Kroese (2021) synthesising qualitative literature in relation to the female experience of secure care across the UK once again highlighted the paucity of specific literature and at times robust methodology but did demonstrate the importance of incorporating literature that included the experiences of those with a learning disabilities (Thomson and Johnson, 2017; Longton and Fish, 2002). These studies brought together allow for a clearer picture of the female experience that transcends diagnosis but also demonstrate concepts such as disempowerment and staff / patient relationships within the secure environment.

# 2.5 The gender approach – the management and treatment of women in secure care and mental health services

The literature would suggest that women are significantly different from men in terms of their clinical presentation. Key areas that have been explored are those of self-harm, levels of violence and aggression, diagnosis and clinical presentation and are more likely to contribute towards staff stress and burnout within secure care settings.

Studies showing rates and prevalence often aim to achieve a direct comparison with a male counterpart. Automatically this tends to aim to prove a complexity when working with women that isn't necessarily there within a male service (Maden, 1996; Alexander et al., 2006). Even papers aiming to demonstrate the needs of female service users once again highlight women as different and often negatively so, for example the "need" for more psychotropic medication to be given to women (Hassell and Bartlett, 2001). It is difficult already to ascertain, based on the more quantitative nature of some studies, and often because of a desire to demonstrate an inequality in care approaches and service provision (Powell, 2008, Sequiera and Halstead, 2001) what the reality

might look like for women, simply because of the comparison with male dominated services. Aitken (2006) seems to touch upon this by highlighting that women are actually further disempowered within the secure mental health setting because of this issue. Aitken argues that it is this discourse surrounding women which provides "unsafe uncertainty" (Fish, 2018), that it is this discussion around the complex needs of women in particular and compared to men

(W)omen patients become constructed as having particularly complex needs, being particularly challenging, and especially vulnerable to overt forms of abuse (all of course relative to men). Women are also constructed as 'too fragile' to be allowed to risk trying out therapies which explore the emotional and relational aspects of being, even at a woman's request. In effect, women are constructed as differently dangerous but more so than men — to services and to themselves. The consequence is that a culture of suppression of rage, anger, frustration, and fear is maintained, as is the communication of women's sense of vulnerability and powerlessness. Women are 'done to' rather than 'being with'. (Aitken, 2006:727)

Yet it would be important also perhaps, particularly when thinking about representing the female through a feminist lens or from a feminist perspective, that the discussion does indeed have this effect, but that it is being had within the construct that is the male service. It is not the discussion itself necessarily that is the problem in highlighting complexity of the women and their clinical presentation as this may be required in order to further advance sound clinical judgement and treatment approaches. However, the setting of that discussion; the context blindness (Vermeulen, 2012) or the inductive paradox that is the male / paternalistic informed service. This can be explored a little further by looking at literature which discusses our view of women, their behaviour and complexity within a range of social constructs and norms.

Adshead (2004) discussed the possibility that women detained within secure forensic services are in fact not too different to men in terms of the prevalence of violence and aggression, thus refuting some of the earlier discussion points in this section. However, Adshead goes on to suggest that it is precisely this point which can often make violent women more difficult to manage, due to the apparent subversion of gender stereotypical roles (2004, p.84). The crime statistics effectively tell us that women commit less violent crimes than their male counterparts (MoJ, 2020). Travers (2013) comments how women have not easily fitted into existing forensic services and Long's work (2011) echoes this by suggesting that approaches to nursing women in forensic services need to employ a

much more therapeutic approach, with more emphasis upon psychological rather than pharmacological treatment, traditionally the key approach to working with males within services (Storey and Dale, 1999).

This point would be supported by Lunsky and Gracey's 2009 study which, although exploring the reported experiences of women with a learning disability in a Canadian psychiatric setting does highlight frequent use of chemical restraint with these individuals. A further study by Larue et al. in 2010 proposed that a lack of knowledge and understanding of the needs of service users and the functions behind specific behaviours may contribute to inadequate risk assessment and increase levels of staff anxiety so that they may be prone to demonstrating a distinct "lack of congruence" (Larue et al. 2010: 213) when making the decision to seclude someone.

The discourse around women is also important to acknowledge when referencing key literature, particularly due to its paucity within this field of nursing. For example, Clarke's study in 1999 clearly outlined the difficult nature of nursing females within forensic mental health settings and acknowledged challenges to staff including prolonged incidents of self-harming or high incidents of violence. However, Clarke terms these challenges as "acting out" behaviours (Clarke, 1999) and already that indicates the way in which the differences in clinical presentation of the female may be viewed by staff and then wider society over time. However, Clarke-Moore & Barber (2009) more recently are able to identify the way in which previous negative interpretations of behaviour including attachment complications with staff members, if cultivated well using consistency and therapeutic boundaries will allow women to become more self-aware and to feel more settled within such environments.

It is therefore useful perhaps to explore in more detail, reviewing the literature, some of these complexities and clinical issues which relate more to women, at least in our professional view. Due to society's expectations of women and the role that they are meant to play, we therefore tend to struggle and feel the need to clinically explain women who commit crime or have significant mental health issues in a different way to men. 'Because we feel differently about women committing crime, we go to great lengths to avoid defining them as criminal, preferring the idea that they have emotional problems; they are mad rather than bad' (Probyn, 1990 cited in Warner, 1996:113). This is also discussed at length by authors including Ussher (1991), Foucault (1988) and Williams et al. (2004). Williams et al. (2004) continues to discuss the diagnostic labelling issue in relation to women's mental health, arguing that they are in fact automatically disadvantaged when they newly enter a service due to our language around mental health labelling and "ward-based jargon" which follow the women through their notes and reports (Williams et al. 2004 : 32).

The concept of madness and mental health is arguably historically a feminine issue. The idea of hysteria and the attribution of mental health deterioration to the biological make up and bias of women is seen through feminist critique and literature exploring the misogyny of women's mental health. Ussher (1991) mentions that psychiatric discourse has always tended to view women as mad while a medical discourse would view men as bad, therefore persuading society that criminals are men and that our criminal systems to deal with this are androcentric by default. Vulnerability factors therefore for women in secure care can therefore stem from not only their lack of representation within systems which favour the male treatment approach, but also from their perceived biological and psychological weaknesses. In addition, women with learning disabilities are vulnerable by the very nature of their position within society (Goodley, 2017).

# 2.6 Issues affecting women's care – Self-harm and trauma

Self-harm in secure units has been found to be prevalent for both men and women (Burrow, 1992) and people who repeatedly self-harm have been described as one of the most challenging groups of patients (Huband and Tantam, 2004). Self-harm can take on multiple meanings and presentations. People with learning disabilities (generally mild or moderate by definition) have described using self-harm as a way of coping, a symptom or disclosure of distress, a physical release from frustration, or a form of self-punishment (Harker-Longton and Fish, 2002; James and Warner, 2005).

Females detained within secure services may be prone to high levels of self-harm and a diagnosis of borderline personality disorder. This in turn may contribute to levels of burnout and stress amongst those nursing them (Hayes, 2007). This is significant when considering the aims of this research study and the decision made by a staff member to use seclusion as a way of managing an increasingly difficult situation (Happell et al. 2011). James and Warner (2005) actually suggest that locking someone up or incarcerating them due to prevalence of self-harm may affect those with disability more than those who are classed as non-disabled. It is interesting that this particular study highlights that using force or segregation may prolong the need for the individual to self-harm and is often seen as punishment for the act, but that the reasons for which individuals report to self-harm would echo the statement above relating to self-punishment, distress and invoking past trauma. There are small numbers of studies relating to the function of self-harm in individuals with a learning disability (not necessarily exclusive to women) (Lovell, 2008; Harker-Longton & Fish, 2002). These are significant to the understanding of the literature surrounding a particular type or group of people as there is relatively little research that can be directly applied to give a clearer or broader picture (Forrest-Lawrence, 2019). Single case-study design has its criticisms (Byiers et al., 2020) and

individual papers often lack validity, show bias through researcher interest and can lack rigour in methodological frameworks (Williams et al. 2018) but their importance is clear due to the representation of a group of individuals within a much wider, often political discussion (Lovell, 2006; CQC, 2019).

The lives of women and the lives of people with learning disabilities as some of the most vulnerable people in society is well documented (DoH, 2012; Levine, 2018, Garland-Thomson, 2005; Aitken, 2006; DoH, 2009; Home Office, 2007). The section above highlights one of the ways in which past experiences may then manifest in terms of how women may cope with their feelings and anger towards others. Women with a learning disability also fall at that intersection where the issues associated with gender and disability meet. They are then essentially doubly affected and oppressed by a society and services which have not been developed with them in mind.

This section will not aim to appraise the literature relating to the impact of trauma and abuse but to highlight the changing landscape of how we are beginning to consider the care and treatment of people with learning disabilities and other vulnerable groups including women and this is in relation to past history and experience. When Linehan (1993) developed her approach to treatment for those with a borderline personality disorder and rooted dialectical behaviour therapy (DBT) in concepts of validation and understanding the impact of past trauma and experience then this began to change the nature of female services (Aiyegbusi, 2002). Women are traditionally more likely to be viewed from a psychiatric perspective when they become involved in the criminal justice system (Stafford, 1999) and this leads to more reliance on defining them in terms of disorders and conditions inclusive of personality disorder (Wilkins & Warner, 2003). The connection between abuse and being female within services is therefore often constructed in past literature in a way that views the women as potentially more of a challenge and requiring tailor-made care. The context of abuse is associated with the impact on the personality which then leads to behaviours inclusive of self-harm or greater levels of violence (Sequiera & Halstead, 2001). Other literature demonstrates how women with past abuse are perceived. Mansell et al (1998), for example, highlights a possible link between abuse and offending in later life, and indeed knowledge of past abuse is claimed to increase risk levels in services (Pollack, 2007). However, the gender discourse does appear to be changing a little more towards more trauma-informed approaches to care and treatment. While we may not see the significant impact on assessment and diagnosis (women continue to be disproportionately represented in terms of a diagnosis of some personality disorders), psychological approaches and the research we see within secure services for females is changing. Understanding the impact of trauma on a person (Mevissen & de Jongh, 2011) then allows us to begin to evaluate the approaches we take to higher levels of stress and potential aggression and supports further call

to integrate trauma-informed approaches into the care of those who need it the most (Keesler, 2014). It is therefore hoped that my research study can also add to this emerging body of literature aiming to understand the lived experience of those who have experienced trauma and how they articulate that within the context of their nursing care.

# 2.7 Seclusion

## 2.7.1 Its meaning and value

"Seclusion refers to the supervised confinement and isolation of a patient, away from other patients, in an area from which the patient is prevented from leaving, where it is of immediate necessity for the purpose of the containment of severe behavioural disturbance which is likely to cause harm to others." (DoH 2015: 26.103).

This definition is taken from the amended Mental Health Act 1983: Code of Conduct. The code also stresses that seclusion should be used only as a last resort and for the shortest possible time (DoH 2015).

The definition of seclusion is important so that we know what we mean when we use the term and also give a definition to seclusion within the context of this research study in the UK. It is important to have this definition to look back on as this will be related to the experiences of women later in the thesis to explore their understandings of seclusion and what it means to them. This definition gives us our boundaries and our benchmark by which to begin exploration of the female experience within a secure hospital setting.

The language of seclusion also involves other terms which are also defined legally within the Mental Health Act and legislation and are subject to rigorous checks and safeguards if used by clinical staff. One of these terms is "Long-Term Segregation" (LTS) which the Mental Health Act Code of Practice defines as "a situation where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and a representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward or unit on a long-term basis" (DoH 2015). What is apparently different at first glance between seclusion and LTS is that LTS can be used within various areas of a ward environment if deemed suitable, for example a bedroom or separate annexe suite and can also be used flexibly allowing some mixing at certain times. Some studies will discuss

both seclusion and long-term segregation within the same discussion or combine rates for the use of both.

Introduced as an alternative to mechanical restraints in the early 19th century (Alty & Mason, 1994), seclusion continues to be a commonly used intervention in psychiatric services (Doedens et al., 2021) and in learning disability services (CQC, 2020) and it is one that continues to incite debate and discussion. Much influential and mainstream literature would label seclusion as a controversial form of containment, often considered by service users to be punitive, obstructive in the development of therapeutic relationships (see Gilburt et al., 2008) and even a violation of basic human rights. It is therefore important that we use literature which has both influenced practice globally and within the UK, made claims that have then been repeated and tested where possible and also look at any literature which might consider not only the experience of the person with a learning disability but also that of the female service user as well. Kinner et al (2017) comments on the seclusion discussion since 2010 and highlights that data exploring its alternatives and reduction success can also serve to show an increase in other such restrictive measures, for example the use of medication to sedate and that this data is more prevalent within Finland and the Netherlands.

In 2014 the Department of Health published "Positive and Proactive Care: reducing the need for restrictive intervention". This document was aimed at a range of individuals, both staff and service users within social and health care services and for whom there is a significant risk of being exposed to restrictive interventions. This document also specifically mentions its application to those who have a learning disability as well (DoH, 2014, pp. 12).

The impact of Positive and Proactive (P & P) appears unclear. It outlines a framework highlighting not only the need for a reduction in particular restrictive practices, including seclusion, but also suggests ways in which this might be approached. This includes the use of Positive Behaviour Support, a framework and concept which has very much entered into the public consciousness and is might almost be described as a trademark and staple approach to supporting those with learning disabilities and associated mental health and autistic conditions (Mafuba et al. 2018). What Positive and Proactive essentially aims to do is to respond to the political and social change which was demanded in the wake of Winterbourne and subsequent Transforming Care (DoH, 2012). A change was coming. Services were supposed to be moving away from the long stay inpatient hospital, beds were to be decommissioned and people supported and offered care within their own communities.

Yet, there continues to be a call for things to change and for restrictive practice to reduce ( NHS 2016, Secretary of State and CQC 2019). It is perhaps far too early to be able to evaluate the influence or impact of policy, guidance documents such as P & P. It discusses the importance of

involving the service user, their families and a range of other professionals to ensure rights are acknowledged and met with the focus of restrictive practice at its core. The document highlights examples of "better" or more ethical practice that may be utilised in order to tackle overuse or reliance upon other methods inclusive of seclusion. These include an overview of the benefits of approaches and projects such as Positive Behaviour Support, Recovery-based models and also Safewards (Bowers et al. 2014). What isn't always clear in this document is how this is then directly or explicitly linked to the type of staff culture or approach that these are perhaps trying to tackle. The section outlining seclusion does exactly that. It defines seclusion and the circumstances in which seclusion should be used under the Mental Health Act. What is unclear is the wider context in which rates of seclusion may rise or the reasons why there may be overrepresentation of the use of seclusion within certain population groups (Bowers et al. 2012).

Positive and Proactive is an important document, although at the time it was published (a key time in the wake of the Winterbourne Scandal) it did come in for a little bit of criticism. Some of this criticism said that it was perhaps over-simplistic in that as guidance only it does not adequately arm services to make real change that is closely monitored and that certain approaches discussed in the guidance, e.g. PBS are not going to tackle some the cultural roots that in fact led to scandals such as Winterbourne (Eales, 2020). Perhaps this is true if seen purely as a reaction to such abuse scandals, so does it really go far enough? Paterson et al. (2014) also suggest that with policy guidance overseen and monitored by local quality and assurance processes, e.g. CQC, real impact is slightly eluded and that monitoring and training approved at government level would be more effective in the long run, citing that those who have previously failed in their monitoring duties are those who continue to be charged with the implementation of this newer guidance and policy.

The Transforming Care impact is also perhaps to be used cautiously within the context of this research study. This is clearly an important policy drive and ethical discussion aimed at improving lives of people with learning disabilities. However, the use of seclusion within some of the services where staff lacked training and service users or patients were not there because of criminal risk to society then this comparison between literature and its participants needs to be carefully compared.

Even more recently the Care Quality Commission (CQC) published its interim report in May 2019 on the use of restrictive practices including restraint, seclusion and segregation for people with a mental health problem, learning disability or autism. The interim report chose to focus on children and young people as well as those mentioned above. The report begins by echoing the Positive and Proactive 2014 document and the importance of positive behavioural support and staff training in reducing circumstances when individuals may become aggressive and require restrictive

interventions as a result (2019). This is cited in line with NICE guidance as well as Positive and Proactive (DoH, 2014). The interim report on the overall CQC review is not extensive and highlights continuing themes associated with poorly trained staff teams, pressure on staff teams and budgets to ensure appropriate community care and avoiding long term detentions in hospital, demonstrating the relatively low impact to date of the Transforming Care agenda on certain organisations and individuals.

In October 2020 the Care Quality Commission (CQC) in England published the "Out of Sight – Who Cares?" report which highlighted the general failure around health and social care across England both in hospitals and the community to properly provide individualised, person-centred care for those with a learning disability and / or autism in relation to the use of restrictive practice. While case studies, vignettes and reviews of levels of prolonged seclusion and long-term segregation were featured there is little captured in the report regarding the patient and staff voice. It is also difficult to see which services they reviewed were particularly being highlighted in terms of recommendations around the implementation of Positive Behaviour Support plans or need to address fundamental local policy change and staff training. What this report does do is to continue to highlight the difficulties faced by those with a learning disability in terms of their involvement in planning and avoiding periods of seclusion and long term segregation. However the report is not exclusive to those with a learning disability yet does acknowledge the diagnostic complexity of those within particular services. One comment within the report stood out relating to this particular review and study. It read:

"In low secure hospitals, there was a particularly distinct group of young women in seclusion or long-term segregation who seemed to have a very similar history, which included abuse or neglect as a child and incidents of self-harm. Before entering adult services, they had been in child and adolescent mental health services (CAMHS), sometimes on low secure wards. These women tended to have a long history of multiple hospital admissions and placements in care institutions over their relatively short lives." (CQC, 2020: p. 7)

This is indeed reflective of the lives of women within secure services and has been discussed earlier in this chapter. The document, while a review and providing recommendations for services and feeding into wider review policy is mindful of the nuances of people with a learning disability and also some gender difference.

Policy and guidance detailing services for mentally disordered female offenders within secure care is certainly not extensive. A number of key documents become evident when searching for influential

policy around this subject. Despite the mention of the plight of such women within the Reed Report (DoH 1992) ten years earlier, it was not until 2002 that the document entitled... "Into the Mainstream" was published by the Department of Health. This document specifically discussed how services for women with a mental health problem should essentially look. While generally discussing the concept of gender sensitive services and a skilled workforce, women within secure services are mentioned in passing while women with learning disabilities receive no more scrutiny than three lines of a document will allow. However, this document is considered important due to its focus solely on services for women. It clearly highlights, albeit fleetingly at times, the challenges that can be faced by staff while supporting women within mental health services. Subsequent policy, namely the Corston Report (Home Office, 2007) and the coveted Bradley Report (DoH, 2009a; Centre for Mental Health, 2014) continue to call for more appropriate care for women supported within secure services and that staff working with this service user group require a skilled workforce with knowledge and training focused around topics such as gender training, borderline personality disorder, self-harm. This kind of generic search led the researcher to then take a look at recent policy outlining the more specific health needs of these women. This included the NICE guidance around long-term support for those who self-harm (NICE, 2011) and those who have a diagnosis of Borderline Personality Disorder (NICE 2009). This demonstrates the lack of policy and guidance relating to women with a learning disability who have additional mental health issues. Despite this, the fact that most women detained in secure services who have an additional diagnosis of a learning disability will be on the whole, categorised as having what is commonly termed "mild" or "moderate" learning disabilities and so much of the policy and guidance can then be generalised and applied to this group of individuals. This should not detract from the evidence which suggests that people with a learning disability will experience additional and significant complications relating to both physical and mental health, as well as difficulties around communication and treatment (DoH, 2009b, Emerson, 2011).

Applying the theoretical frameworks previously discussed have allowed for these policy documents to be explored and discussed. For example, allowing for critical theory to take in to account the social and political constructs within which these particular women are nursed and offered treatment. However, this framework, while incorporating a feminist perspective also, allows me to identify and review literature pertaining to individual experiences within the wider context.

Policy and guidance are important to understand the political and legal context that influences changes in care provision and the way in which practice is directed. It is clear from reports in particular that often poor practice is the catalyst for change and review and either reigniting or

beginning a new debate around issues such as the use of restraint and seclusion. However, it may be that we can also begin to acknowledge the importance of these documents and the events that guide them as reflective of the social and institutional discourse that surrounds them. Within the introductory chapter and establishing epistemological positioning, Foucault and his discussions around power and knowledge was discussed. This is also perhaps important to revisit here within the literature review when exploring discourse and debate on the use of seclusion. It can then also be applied to the cultural context of mental health secure services, forensic inpatient provision and also caring and treating those with a learning disability. In Isherwood's review in 2006 on the research to date on restraint and seclusion in both mental health and learning disability services, some of the studies and literature mentioned in this review is also present but he also reflects on the importance of viewing this within a cultural and social context. Isherwood mentions Foucault and the possibility that institutions are "powerful repositories of such discursive practices". He advocates for further exploration around the meaning and value of seclusion taking this power and its influence on previous knowledge. This could mean that a further cultural exploration around experience could give deeper meaning to further research. My research intends to do exactly that, exploring the lived experiences of women, ensuring their own voices and perspectives are explored as far as possible within the study. Meaning will be derived from considering their experiences within the context of the hospital setting.

# 2.7.2 The Wider Context: policy and the global debate

Table 1 - Timeline of key UK policy documents referred to within the literature review

Policy name (common reference) and date	Brief Overview
The Reed Report (DoH and Home Office, 1992)	A joint review by the Home Office and Department of Health of services for mentally disordered offenders and others requiring similar services. Reed proposed that these and other needs can be met only by a broad and integrated range of health and social services that also include the community services aimed towards rehabilitation. It supported a multiagency approach with over 200 recommendations for change.
Women's Mental Health: Into the Mainstream. (DoH, 2002)	Women's Mental Health: Into the Mainstream emphasises the importance of listening to women. Their voice is highlighted throughout the document together with examples of services across the country that are genuinely empowering women and responding to their needs. The aim of the report was to help develop a framework for higher quality, comprehensive services aimed at women on a more individual basis.
The Corsen Report (Home Office, 2007)	Baroness Corston was commissioned by the Home Office to study women in prison and what measures could be taken to avoid women who have certain vulnerabilities being involved in offending behaviour as a result being sentenced to prison. One of the biggest achievements of the Corsten Report was to establish a network of Women's Centres offering specialist and holistic support to women affected by the criminal justice system
The Bradley Report (2009)	The Bradley Inquiry looked into the extent to which offenders with mental health problems or learning disabilities in England could be diverted from prison to other services and the obstacles to such diversion. The report makes recommendations on the organisation of effective court liaison and diversion

	arrangements and the services required to support them.
Transforming care: A national response to Winterbourne View Hospital (DoH, 2012)	The Transforming Care Programme began following the review into the abuse at Winterbourne View which also resulted in 11 criminal convictions for staff members.  Conclusions drawn that influenced the proceeding Transforming Care agenda centred around realising that people with learning disabilities and / or autism were detained for too long in secure hospital settings inappropriate to their needs and level of risk and that people were placed too far from family and their community.
Positive and Proactive Care: Reducing the need for Restrictive Interventions (DoH, 2014)	This document looked to identify key actions and areas that required support to better meet people's needs within social care and health services who may be subject to restrictive practice and interventions. It also sets out mechanisms to ensure accountability for making these improvements, including effective governance, transparency and monitoring. Workforce guidance was set out to change culture and leadership within healthcare service aimed at providing a more evidence based and supportive approach to individual care.
Out of Sight – Who cares? Review of restraint, prolonged seclusion and segregation for people with a mental health problem, a learning disability and / or autism. (CQC, 2020)	This report continued to highlight serious concerns around the use of restrictive practices for people. It demonstrated the lack of community services, which can provide early intervention, crisis support and support for people living within their communities, meaning that people are more likely to end up in hospital. The review highlighted good practice and urged services to move forward with recommendations for care.

The debate around seclusion as a valid and ethical measure to deal with the management of violence and aggression within secure mental health settings continues. It is often viewed as a contentious issue with many influential voices calling for an alternative and / or even the complete elimination of seclusion within hospital settings. The use of seclusion and people with learning disabilities and autism has been highlighted more frequently in recent years and will be discussed in more detail further on in this chapter. An opinion piece by Tamminen in 2014 urged the reader, the practitioner and the commissioner to really seek to "know" the process of seclusion rather than making a snap ethical decision and sitting on one side of the argument only. Tamminen argues that

the reduction of seclusion which has been a financial and political aim for many countries, services and institutions over the past two decades is just the beginning and the tip of the iceberg in order to really understand seclusion and therefore to understand what might be a better way of designing service and care provision for those individuals who are currently subject to it. Tamminen states that "We should not reduce seclusion and restraint because of fear" (2014:200). It is an interesting thought and not one that Tamminen really expands upon to define what we are fearful of other than suggesting litigation and responding to an ethical and moral debate. However what is key to this piece is the focus on clinical decision making, individual factors (e.g gender or disability) and that these should in fact inform changes to the use of seclusion and restraint.

Bowers et al. (2010) work was consulted as this appeared to be a rarer study which attempted to ascertain the use of seclusion and "time-out" across a large number of English acute Psychiatric units. Bowers himself appears to be fairly prevalent in recent years within the debate around the reduction of particular restrictive practices within mental health settings and attempts to ascertain their true use within these practice areas. It is particularly interesting that a further study (Bowers et al. 2012) sought to explore the potential for replacing the use of seclusion with "time out". This again is in line with the current political drive to demonstrate a reduction in the use of those restrictive practices more commonly seen as perhaps more punitive in nature (Moran et al. 2009; Sequiera & Halstead, 2001). While these studies other than the Sequiera & Halstead study do not discuss any findings in relation to a forensic or secure setting in particular or those who have a learning disability, they do tend to represent much of the recent mental health literature looking at both service user and staff perspectives on the use of seclusion. Studies such as those by Happell & Koehn (2011) and Meehan (2004) appear to show that staff perceptions and service user experiences of the process and use of seclusion is generally at odds and that further discourse needs to occur with both groups in order to ascertain more effective ways to address the implementation of restrictive practices. Jones and Kroese (2008) while echoing this disjointed approach to the use of restrictive practices between staff and services does in fact focus on the perceptions of those with a learning disability. However, the quantitative methodology employed within the particular study does perhaps limit its generalizability to other groups of individuals due to the specific conditions focused on within the participant group, although the authors do acknowledge the therapeutic milieu which might warrant further exploration in terms of care planning for the future (Jones & Kroese, 2008).

A qualitative Canadian study by Holmes et al. in 2004 aimed to understand the experiences of seclusion from the perspective of the patient themselves and to better interpret how they viewed

seclusion and the reasons for its occurrence. Holmes alludes to the fact that a particular debate around the use of seclusion as a therapeutic intervention versus its use as a punitive measure by staff is still on-going (Happell, 2011). Recent UK studies, e.g Bowers (2018) once again discuss the function of seclusion and its place in the treatment of mentally disordered individuals. What is quite striking about Holmes's study is that within the discussion, he appears to demonstrate the fact that seclusion is often the end point, severing and disrupting communication between patient and nurse. What appears to be implied is patient perceptions of staff as having brought them to this point, a point which at times seems utterly traumatic. Holmes uses the words "abandonment" and "rejection" in connection with the patient experience of seclusion and very much connects this to nursing care as its very essence.

While Holmes mentions fear among key factors that may influence a nurse's decision to implement the process of seclusion, the emotional impact on staff is not something that he chooses to consider within this particular paper. While my study will focus on the lived experiences of the women themselves, I have incorporated the perceptions of their relationship with and the role of the nurse within interview. Ching et al. (2010) introduce the current climate and the use of seclusion through highlighting that even though we are perhaps beginning to identify some key themes and concepts when considering what will support to reduce the use of seclusion, what does not feature in this list are the clinical features of the service users / patients themselves. While other studies (e.g. Holmes et al. 2004 ) discuss particular mental health conditions that may increase the use of seclusion with some individuals, particular approaches to how these are then worked with in relation to restrictive practice are not reflected here. However, an emphasis upon knowledge, e.g. around alternative methods to manage aggression, de-escalation techniques are mentioned briefly within the study but not given further scrutiny, perhaps due to the methods employed to elicit results. Once again the potential importance of additional qualitative data is implied. This is further demonstrated by the Meehan study from 2004 who outlines reasons that staff may choose to seclude a patient and this at times at odds with the very definition of seclusion which is that of being a last resort to manage extreme violence and keep the patient and others safe.

Van der Merwe et al. (2013) state in their opening summary that staff and service user perspectives of seclusion are almost completely at odds with each other. What this review of the literature does however reiterate is the importance of communication between staff and patient during the use of seclusion, reflecting the findings of Holmes et al (2004) almost a decade previously, in fact Holmes is one study that is considered within the 2013 article. What Van der Merwe et al do point out however is that for some patients, seclusion is not always perceived as a negative experience. They

reviewed literature that highlights the potential for patients to feel safe and protected while detained in the seclusion room. So why does the seclusion room invoke these feelings for some individuals? This is not entirely clear from the results presented within the Van der Merwe review, although what is noticeable is that all papers cited within this discussion point are predominantly written either in the 1980s or early 1990s. Does this in fact reflect distinct changes in the practice of seclusion or a change in culture around patient perception and the use of seclusion within secure hospital settings?

In 2002 Swinton and Bell propose that seclusion is in fact an effective means of managing violence and aggression in individuals. They state:

"As practising clinicians we believe that seclusion is an effective, acceptable and safe way of minimising the risk of violence in patients whose behaviour indicate that violence is imminent. The only way of actually proving that seclusion is effective would be an experimental study in which some patients are randomly not secluded when they otherwise would be. The outcome measure would be the degree of harm that those patients cause to other patients and staff. We do not believe that such a study can be undertaken and therefore it is difficult to prove conclusively that seclusion is effective." (Swinton & Bell, 2002: 273)

This is now twenty years ago regarding the use of seclusion and precedes the discussion and debate that followed over the next decade and reduction of seclusion. The interesting comments from the Swinton & Bell (2002) article relate to the belief that seclusion is effective when violence is imminent which appears maybe contradictory to the concept of seclusion as the last resort as stated in the Mental Health Act Code of Practice (DoH, 2015). However, what this does allude to is the idea that seclusion is inevitable at times, although there is no particular mention of gender here in this article, and that debate should shift towards how seclusion can be used more effectively and incorporate the needs of the individual. Swinton and Bell go on to comment that what is perhaps important is therefore looking at ways in which seclusion can be made less stressful for individuals. While the excerpt above quite clearly seems to demonstrate a belief in a quantitative approach in order to really ascertain effectiveness of seclusion as a method of managing violence, it is also my own thought that concentrating on seeking a less stressful approach to using seclusion would not necessarily need this kind of methodology. This is interpretation on my part, and based on my own anecdotal discussions to date, founding on unstructured clinical judgement and experience. This piqued my interest due to the concept of seclusion as a chosen and needed end point for the

management of violence and aggression, as well as raising some interesting ethical questions relating to robust research. It is though, important to bear in mind the source and the opinion aspects of this small piece of writing which was in fact a response to an article by Mason and Whitehead (2001) regarding seclusion and women at Ashworth hospital.

Fast forward into the next decade and Brophy, Roper et al. (2016) mention the use of seclusion and it sometimes being justified as a "necessary evil" (2016; p.4). However, in the same year Chan (2016) considered the use of seclusion amongst other restrictive measures and people with a learning disability or "intellectual impairment". Chan commented that discussions around seclusion and its use with this population often reported that it was an "occupational hazard". Once again, we have yet another marginalised group in society, regardless of gender whereby particular attributes have been given to the group and a lack of research has meant there is little to contradict this. While the discourse around the use of seclusion appears to have waned a little and some of this may be in part to the documented early successes of initiatives such as SafeWards (Bowers, 2014) and the emergence of trauma-informed care discourse highlighting further emphasis on understanding experience and life history. Seclusion references continue to call for the reduction and / or elimination of this practice (Fish, 2018) as well as more understanding of the experience of those with traumatic life histories or particular clinical diagnoses. The discourse does not appear to be different from those negative portrayals of seclusion and restrictive practices from much earlier discussions (Goffman, 1961; Brown and Tooke, 1992) but has moved on to include discussion around trauma, power and enablement (Vermeulen, 2012, Frankish, 2019). Even approaches aimed at the more general learning disability population or even children have begun to focus on trauma and engaging in relationships with others in order to address difficult life experiences (Hughes et al. 2019). This is important because my study will consider these restrictive practices within a more gendered focused and trauma considered discourse, reflective of the current assessment and treatment approaches to this particular group of individuals.

# 2.7.3 Seclusion and women: preliminary review

VanDerNagel et al. (2009) refers to gendered rates of seclusion and offers a little insight into this. While it is acknowledged in this study that men are more likely to be secluded than women, then women will often be secluded repeatedly over shorter periods. VanDerNagel refers to this as a "behavioural approach" (2009: 408) aimed at managing the immediate threat of violence or the

persistency of the threat of violence demonstrated by women in these settings rather than seeking to understand the reasons behind the behaviour itself. By responding to particular behaviours using measures such as seclusion then this will potentially skew our perception of women and the need for using seclusion with them. Studies may vary in terms of the consideration of frequency or prevalence of seclusion and its relationship to gender but this quote is interesting as it suggests that our use of seclusion does not fully acknowledge the gender difference.

With key psychological theoretical frameworks in mind and the aim of this study, majority of the literature chosen to be initially reviewed was of a qualitative nature. Literature aimed at adopting a qualitative methodological approach and in particular a look at individual experiences within the context of the social construct of the secure setting was of particular interest. Appropriate CASP analysis tools were utilised in order to be able to ascertain the key findings as well as any potential strengths or weaknesses of some of the literature.

Females detained within secure services may be prone to high levels of self-harm and a diagnosis of borderline personality disorder. This in turn may contribute to levels of burnout and stress amongst those nursing them (Hayes, 2007). Happell et al. (2011) began to explore the correlation between attitudes towards seclusion and rates of burnout of nursing staff. While predominantly quantitative in approach and analysis, this piece of research certainly demonstrated links between particularly challenging behaviours and the use of seclusion and the reasons nurses may choose to make the decision to seclude someone. While gender is only mentioned fleetingly, behaviours including selfharm and prolonged incidents of verbal abuse are certainly prominent when looking at the reasons service users may be secluded, echoing the reasons given by Nicholls et al. (2009) as to why women may be subject to more frequent incidence of seclusion. The same study by Happell et al. (2011) also attempted analysis of service users feelings while in seclusion as perceived by staff nursing them. Feelings including fear, a lack of control and anxiety feature prominently. This literature provides support to studies conducted further back in time when patient experiences of "solidarity" were explored by Chamberlain (1985) as well as more up to date studies (Holmes et al. 2004) where the patient often viewed the use of seclusion as a form of punishment. Long et al. (2015) highlight the current need and priority to reduce the use of seclusion within female secure services, although this study does not focus upon individual patient experience.

A significant piece of research taking a rare look at violence, physical interventions and women with a learning disability within psychiatric settings highlighted a) the disproportionate use of restraint, seclusion and rapid tranquilisation used with women in psychiatric settings (Sequeira & Halstead 2001). This study found that this appeared to be the case regardless of the presence of a learning

disability or not, thus generalising more in terms of gender than anything else. This study does acknowledge that there may be a number of factors which perhaps skew these findings, such as the relatively low concentration of female patients or even the desire to suppress violence in female patients due to society's discomfort with this type of violent scenario (Sequiera and Halstead, 2001). This piece of research is perhaps more significant due to the discussion around the anxiety, pain and distress felt by those women who had a learning disability as well as its more specific focus on women with a learning disability, allowing this work to be cited a number of times within other non-UK studies (Van der Merwe et al., 2013). A study by Powell et al. (2008) goes on to echo the distress recorded in women with a learning disability who are subject to physical restraint and seclusion in particular. This study also highlights the apparent high incidence of the use of seclusion with mentally disordered service users in secure settings who also have a learning disability, a point which is reiterated by Boumans (2012) reviewing the nursing decision making process around seclusion and patient characteristics which may influence this process.

This point also appears also to be relevant to female service users in particular, who, according to Nicholls et al. (2009) are often secluded more than men "as a result of acting out" (p.32), though Nicholls cites a lack of transfer options within female services generally as reason for this, rather than the overly aggressive nature of female service users. However, bearing in mind the consideration of the research paradigm that is being adopted it is important to consider this from the perspective of the feminist researcher. The idea of "acting out" indicates the consideration of the female offender within the construction of the ever present traditional male service. A gender data gap here means that musings or wonderings such as those perhaps by Nicholls do not necessarily consider the reasons behind seclusion and the female service user but simply make a comparison against the information we have on males. There is little exploration of the experiences of females in being put into seclusion and appear to along with Boumans's (2012) observations imply that female diagnosis and female character is responsible for a skew in seclusion rates within hospital settings.

Exploring the staff context, literature also acknowledges that dealing with high and frequent levels of violence and aggression within secure forensic hospital settings sets particular challenges for those working there. In 2007, an article by Foster et al. attempted to ascertain the prevalence and incidence of violence against staff within inpatient settings and then to explore the methods by which staff endeavour to deal with these. Taking a look at the UK, Foster et al. highlighted that it was most commonly nursing staff who were the recipients of violent and aggressive behaviour. Nicholls et al. (2009) also highlight difficulties faced by staff when faced with female violence and

aggression as their study demonstrated that "women were more likely to aggress when engaged with staff" (2009, p.32). However, what is not discussed by Foster and is alluded to in other studies e.g Aiyegbusi (2020) and Beber (2012) is that women have often to deal with trauma and abuse historically which they attribute largely to gender along with background and in Beber's case an additional diagnosis of learning disability (2012).

Ali and Adshead (2022) discussed the possibility that women detained within secure forensic services are in fact not too different to men in terms of the prevalence of violence and aggression but that our social constructs of violence contribute to the way in which services then respond thus refuting some of the earlier discussion points in this section. Ali and Adshead (2022), writing currently also acknowledge the trauma-informed approaches to services being adopted more now in female services as opposed to male, arguing that this is once again reflective of how society should view females within the criminal justice system. However, Ali and Adshead go on to suggest that it is precisely this point which can often make violent women more difficult to manage, due to the apparent subversion of gender stereotypical roles (2022, p.7). This point would be supported by Lunsky and Gracey's earlier 2009 study which, although exploring the reported experiences of women with a learning disability in a Canadian psychiatric setting does highlight frequent use of chemical restraint with these individuals. This again indicates treatment approaches that may have developed on the back of male dominated services and influences. A further study by Larue et al. in 2010 proposed that a lack of knowledge and understanding of the needs of service users and the functions behind specific behaviours may contribute to inadequate risk assessment and increase levels of staff anxiety so that they may be prone to demonstrating a distinct "lack of congruence" (Larue et al. 2010, p.213) when making the decision to seclude someone. This apparent lack of congruence is suggested within an article by Rangecroft et al. (1997). The study that took place in a hospital for people with learning disabilities in the north east of England suggests that women tend to account for a higher percentage of seclusion incidents that happen within such institutions. While gender is not a specific focus of the study, the few statistics looking at the prevalence of seclusion within that particular hospital population make note of the imbalance despite the smaller female population being treated at the hospital. Again, this would perhaps point towards different needs and while the article suggests that this may link to the learning disability population, it is perhaps worth considering the needs of the women in this study.

"Despite concerns about the use of seclusion, the results of this survey suggest that procedures that remove the patient from the environment contributing to the disturbance may have certain advantages in this population" (Rangecroft, 1997: 275)

Adapting a feminist lens to the literature can allow us to at least begin to consider that gender could lead to seclusion being used differently by the population / participants themselves but could also guide the way in which methods may be utilised to gather data. This could mean a research study beginning to look at the experiences of seclusion for women with learning disabilities in particular. My study has focused its questioning and aims around the validity of seclusion and the function of seclusion outside of the policy context within which we are generally presented with our knowledge of the seclusion experience to date.

## 2.7.4 Seclusion and people with learning disabilities: a preliminary review

The literature pertaining to seclusion inclusive or exclusive of other restrictive clinical practices and those with a learning disability is not extensive. While much literature can and should be applied to this population as it is as much relevant to their experience and care as to anybody else's it is also important that we are able to consider people with a learning disability so that we can better understand their needs and experiences, particularly if at times different to those who do not have a learning disability.

Few studies discuss the experiences of people with a learning disability and seclusion. Even fewer have been written within the last 10 years as the move towards implementation of the Transforming Care agenda and post Winterbourne View meant attention moved away from understanding the nature of seclusion to discussing ways of ensuring people were no longer in hospital or no longer subject to these kinds of restrictive practices. Additionally, most literature that was based on primary research either did not use a qualitative perspective or was from somewhere other than the UK. My study aims to fill the gap here due to a dearth in literature, particularly of a primary research nature that could support further knowledge that services can apply to their practices around seclusion. Those key pieces of evidence that were UK based were either not primary research studies, not peer reviewed or stood alone.

In this section I have therefore included qualitative research relating to patient and / or staff experiences but from outside of the UK also as well as studies which try to show prevalence and differences in the rates of seclusion or what leads to seclusion. This work is often of a less qualitative nature but does at times signify that seclusion can mean something different for the learning disabled population or that issues linked to seclusion as previously identified may be more prevalent within this group.

Fish's 2018 paper on her ethnographic study and the experiences of a group of women with learning disabilities in a secure hospital in the UK comments on the scarcity of studies that capture the voices of people with a learning disability and seclusion. She points out that literature is dominated by the psychiatric milieu and while important as background information does not take into account the "unique history of learning disability" (Fish, 2018: p. 140). Fish's research which touches upon the experience of seclusion for these women shows that transcription data from interviews can be limited due to the ability of the women to describe and articulate their experiences at length, however it gives an insight not previously seen in primary research and suggests that seclusion may not always be used as the "last resort" it is intended for. Fish's conclusions echo those of previous more generic studies either about women or people with learning disabilities (Sequiera & Halstead, 2001) which focus on the possibility of the experience being traumatising and distressing.

It does identify this to some degree from a gender perspective that allows us to consider the lives that the women may have had leading up to this point and the need for clear explanation prior to and post seclusion so that staff and patients both understand why seclusion is being used and how. Once again Fish comments on the power relationships present which are echoed by Isherwood (2004). However, from a feminist perspective, is this different for women themselves or due to their learning disability and lack of understanding of some of what may be happening to them? What does seclusion really mean to these women and how can we build upon therapeutic relationships to support with the process of seclusion or to avoid it? Fish suggests along with others as mentioned in the previous section that for women the issue of trauma is such that seclusion may be a slightly different experience for them. We could also link this into the lives of people with a learning disability who have more limited understanding and need more advocacy to communicate their feelings, needs and experiences (Emerson, 2011). However, one small study is not always sufficient to generalise these experiences to a whole population. My study aims to support previous work such as that by Fish. What Fish's study does do however is to reflect some of the findings of the CQC Out of Sight report in 2020 which highlighted systematic failings in care and inappropriate use of restrictive practice inclusive of seclusion across various care settings looking after people with learning disabilities across England.

# 2.8 Chapter Summary

The literature review has understood the literature pertaining to the use of seclusion generally, the lives of those with a learning disability, the lives of women detained within secure services and how all of these studies can converge to provide a more detailed picture of the lives of women with learning disabilities and how their experiences relating to seclusion can be explored so that I am able

to generate relevant and supportive knowledge through capturing their unique experiences. It is clear from the paucity in specific literature relating to their lives, and in particular how they experience seclusion that further qualitative enquiry is warranted. Adopting a feminist paradigm to the study inclusive of the way in which literature is examined has enabled me to present the existing literature so that trends or gaps can be questioned in relation to gender and methodological approaches.

# **Chapter 3: Methodology and Method**

# **METHODOLOGY**

#### 3.1 Introducing the methodology chapter and the qualitative approach chosen for the study

## 3.1.1 Revisiting aims, objectives and positionality of the researcher

Chapter 1 set out my foundations of the research, exploring theoretical perspectives in order to address positionality. This was demonstrated through ontological and epistemological underpinnings and leading to a discussion that positioned me within a constructionist and feminist framework. Having positioned myself as a researcher within the feminist paradigm, taking into account the nature of the research subject this has led to the use of Case Study methodology to inform the research process. This chapter will also address the principles of feminism are that would be taken into account when choosing a methodological framework.

Other approaches were considered and rejected on a number of different grounds. It was mostly important that the research approach chosen fitted with the position identified within ontological and epistemological discussions and the world view of the researcher. For this reason approaches such as action research and grounded theory did not fit well. Grounded theory, for example meant that it may be appropriate to explore the process of seclusion or what the women may experience but did not embrace the fact that I believed both the researcher and the participant should be involved in generating new knowledge and understanding what was happening. Equally, while ethnography would seem at the outset certainly appropriate for this study, pragmatic reasons both from my own personal situation as a researcher and the nature of the services I was in meant that prolonged field observations may be quite difficult. Interpretative Phenomenological Analysis was also a possibility but the reliance on the depth of interview and its own approach to analysis meant that this may be more difficult with a group of women with learning disabilities.

# 3.2 Finding my methodology within a feminist framework

## 3.2.1 The feminist lens and this study

Below is a summary of the principles I have incorporated, the background to the feminist principles applied to this study and how they have contributed to ensuring a robust methodological approach

and the choice of appropriate methods in order to capture the "voice" of these women. Some of these principles are considered within the ontological positioning of myself as researcher and highlight the approach to research and the way in which I behaved within my interactions with the women. This included making preparations to ensure there is a lesser hierarchy within the data collection process. Examples of those would be considering my dress, allowing the women choice of interview room if possible, whether I would hold an alarm and keys as other staff and also considering exchange of personal information between myself and the participant. Other principles are aimed more towards finding an adequate way in which to collect data to ensure maximum validity which means finding a way to capture the thoughts of these women who may have some verbal communication difficulties and require support to understand what is being asked of them. Other principles, such as empowerment as outlined within the introductory chapter and to seek to change lives for the better are also tied into the methodological approach and ensuring the women are facilitated to participate. There are those that lean towards particular types of qualitative methodological approach as being particularly inclusive in capturing the voice of the individual or group of individuals, especially considering the historical narrative of people with a learning disability (Fish, 2018; Goodley, 2000). These two writers, for example, employ ethnographic research, and in Fish's case feminist ethnography in order to gain a deeper insight into the lives of those they are researching. Due to wishing to speak with women across a range of different hospitals and ward environments I did not feel that I had the time to engage in the kinds of in depth observations with in depth interviews that ethnography would require (Angrosino, 2004). It was therefore important to find a methodological approach that would address some of the literature paucity in the field and acknowledge the importance of the researcher / participant relationship and the limitations of the women's communication and previous research experience (Walmsley and Johnson, 2003).

Considering disability and potential issues around communication is also important. Jagger (1997) is just one feminist writer who describes the consciousness of the feminist researcher in relation to power and hierarchy. Given my outlined epistemological position and the importance of my previous knowledge and experiences in being able to gather meaningful data, then consideration of the potential power relationship is likely to be very important, also meaning that a Foucaldian approach also becomes important to further interpretation and discussion further into the thesis (Burr, 2006). Breaking down any hierarchical boundaries that may exist between the researcher and the participant is an important part of feminist research and feminist approaches to research (Oakley, 1993; Wise, 1987; Engoren, 2002). A more in depth discussion might begin to deconstruct social meanings within the context of social discourse (Foucault, 1972) and poststructuralist theory

(Engoren, 2002). What this essentially means is that by thinking about social constructionism (Burr, 2006) and the fact that from a feminist perspective, knowledge and truth are inextricably linked to the concept of power (Dickson, 1990) I am more likely to be able to reflect what these women are trying to express. Dickson discusses the importance of using the idea of the relationship and power in order to really consider language and the way in which the researcher might approach an interview or a discussion within their research.

This links directly back to my own skills gained from being a learning disability nurse and an educator. While this will undoubtedly allow me to facilitate some good communication and conduct some interviews with the women, it is a little worrying that nurses are usually the ones that will make the decision to seclude an individual (Happell, 2011) and therefore that hierarchy may be reinforced simply by this fact alone. However, as we will see, another important facet of feminist research is that of reflexive thought and writing and that through this process, and continuing to question my methods as a way of ensuring the women do not feel threatened or overpowered then I hope to improve the objectivity of my research and allow the voice and narrative of the women to be heard. Jagger actually goes so far as to say that researchers embracing feminist methods in this way (reflexivity and embracing of emotions and feelings) have gone on to in fact "forge new epistemologies of knowledge by incorporating womens' lived experiences...into the knowledge building praxis" (1997: 202).

# 3.2.2 Reflexivity, safeguarding and nursing

The introductory chapter allowed me to introduce myself and to begin to use this information in order to establish my ontological and epistemological position from which to begin this study. I identified myself as a learning disability nurse and that this role and the knowledge it gave me was crucial in conducting this study the way I believe(d) was right, both from an ethical and practical point of view. This standpoint was important in completing my ethics application and gaining ethical approval for NHS research. When asked by the ethics committee what I would do should any difficult disclosures occur during the interview process or if a participant were to become particularly distressed, I was able to use my knowledge and skills as a learning disability nurse to adequately assure that this would be dealt with efficiently and effectively at the time. With regards to the role of reflexivity within this context, using this as a strategy should I encounter any potential safeguarding issues that may in fact prevent effective interviewing or by default even disempower the participant (Burgess-Proctor, 2014) then I could hopefully prevent this from happening.

Reflexivity, reflexive writing and carefully considering safeguards could hopefully offer further ethical protection. It is interesting that my methodology including reflection certainly supported this standpoint and was certainly effective in gaining my ethical approval, however, reflection has also led me to question whether this further ethical protection is in fact warranted and how much does this viewpoint and overt risk awareness reflect our current societal view of the disabled, traumatised, vulnerable and those detained under the criminal justice system? While some of the challenges and pitfalls of adopting feminist research have been discussed previously in the thesis, the role of reflexivity is key in supporting the robustness of feminism for me as an overacrching paradigm to my methodology and methods. This in turn is vital for allowing knowledge to be produced that can then be applied or used within the nursing environment.

Stanley and Wise (1990) while not discussing any particular context mention that analysis within feminist research centres on the "explication of the 'intellectual autobiography' of the feminist researcher" (p.209). Letherby (2003) goes on to suggest that the data, or in my case, interview transcriptions, care notes and anecdotal staff discussions are complex in nature. Coupled with personal views and experiences the role of reflexivity is key in extracting all of this data to make some sort of real sense and useful knowledge that has to some degree stayed true to both our methodological approaches as well as the experiences of the participants themselves. We are also representing the views in our writings of, and certainly in my case, people who perhaps struggle to communicate or have little knowledge of processes or even the real reason for the research.

Reflexive writing allows this power struggle and intellectual superiority (Letherby, 2003) to be faced and challenged where necessary. To put this into some context, I have had to try to analyse the way in which I felt, viewed and therefore interpreted the words of particular individuals and using writing and then to review this has helped me to make some sense of my own role. Below is one short, and early example of this following some initial interviews.

Burgess-Proctor (2014) equally raise the difficulty of processes and protocols within the negotiation of the ethical questions of research and designing a study which is true to its aim and stays true to the researcher's epistemological and ontological positioning. Within this piece of writing it is argued that any conflict arising from such red tape in order to safeguard individuals may be by default traditionalist and positivist in their approach, thereby being in direct conflict with the aims and methodological approaches of the research. Burgess-Proctor goes so far as to say that "safeguards may actually reinforce disempowerment" (2014 p.345). She then suggests ways in which the researcher might challenge and begin to overcome this potential problem. One is reflexivity. Another is the ethic of care, worth mentioning as this is directly aligned to my epistemological stance

using my own nursing background. But reflexivity is a process by which the quality of the methodology and method can by scrutinised, rather than simply just reflecting on experience, feminist reflexivity has at its core the desire to empower the women through use of language and seeking meaning through analysis within the context of the participant / researcher relationship. My interpretation of this for my own study is that writing reflexively during the process will allow meaning to emerge not only from the language of the women but the way in which their answers are sought, the way in which I use my own knowledge to interpret their words and allowing me to explore the context around the research more carefully as I conduct this study.

#### 3.3 Finding the appropriate methodological framework

## 3.3.1 Case Study as the methodological framework

I will now discuss Case Study as a methodology, linking this from my feminist paradigm / framework which I have revisited in this chapter and then discussing this more closely to my own research study. I aim to show the influential theories and writings which make this an appropriate and workable choice for my study as well as some of the more practical applications shown in literature which highlight its usefulness and robustness for nursing research in particular.

Case Study, while looking at a particular phenomenon or concept much like other methodological approaches has an emphasis on using multiple sources of data in order to analyse features of a particular group, individual, culture to even include political and social forces (Lovell, 2006). Simons (2009) refers to the multiple sources of data as an "exploration from multiple perspectives of the complexity and uniqueness of a particular project" (p. 21). Cresswell (2007) argues for Case Study research to be considered as a methodology / methodological approach within its own right in alliance with Stake (1995). This is further supported by Taylor and Gregory (2015) who discuss the varied use of Case Study, as well as its under use within the field of nursing. Like Cresswell, although perhaps more simply, they embrace Case Study as giving rise to qualitative methods which can be drawn together by the researcher to suit their requirements in order to best tackle, and hopefully achieve their research aims.

I found Thomas's (2011) comment, referred to in the Taylor and Thomas-Gregory article (2015) useful as he believed that Case Study as a methodology, rather than simply a collection of methods, does not always seek therefore to generalise findings, although it concerns itself with concentrating on "the thing" (Thomas, 2011), whether that be an individual, group, or even concept. This is an interesting perspective as generalising is often viewed as offering further reliability and validity to a

research study (Robson, 2015). However, as a qualitative approach it can offer transferability which provides a generalising of sorts by offering insight that can then be useful across other fields or research questions. In this instance, this is seen as a positive aspect of Case Study. This is further supported by Lovell (2006) who argues that even the individual case study has the potential to offer an insight into a conditions and concepts that can be applied or transferred to similar cultures and practice. Taylor (2014) seeks to clarify this benefit as meaning that a phenomenon can be explored from a variety of different perspectives.

Case Study has the advantage of enabling me to acknowledge the similarities between the women I interview, as supported by a range of literature, yet to be able to carefully consider their unique perspectives which may in fact differ significantly from one another and this is supported by theorists of Case Study research such as Robert Stake who always acknowledges ethics associated with vulnerable participants (Stake 1995: p.59). As previously discussed with regards to incorporating a feminist approach to the way in which I conduct this research, there is always the possibility that these women view the world very differently from me, from each other and contradict the aims of feminist approaches (Braun & Clarke, 2019). Case Study as a methodology / methodological framework will allow me to consider each of these women, either explicitly as an individual or as part of their own unique group and community before any themes, generalisations or recommendations can be made regarding care and care outcomes. Case Study as laid out by Stake (1995) also enables reflexive observations, professional knowledge to feature as part of data analysis while certain aspects, for example the interview data itself will mean that qualitative analysis approaches can be applied across the chosen unit of analysis or case and used consistently across the triangulation of the different data types in the form of coding and theming.

At this point it is perhaps useful to bring in the concepts of reliability, credibility, confirmability and transferability more generally within qualitative research (Lincoln & Guba, 1985; Houghton et al., 2012; Abma and Stake, 2014). All qualitative research, regardless of chosen methodological approach or process should seek to realise these concepts so that this research is capable of producing positive change and can inform future practice. Stake (1995) and Yin (2003) both argue that the Case Study methodological approach, regardless of framework used will allow for information to be checked and re-checked and also considered from different angles. Stake's view on Case Study research then also adopts the reflexive approach as yet another way to bring rigour to the data and the findings.

So how does the theoretical underpinning of Case Study as a research methodology serve my own study and its aims? Well, firstly, Robert Stake makes full use of the role of the reflective researcher

in order to fully analyse any data gathered (1995). Stake believes that stories of the researcher journey are just as important within the research and that researchers are themselves advocates of their participants and those they represent. He relates this specially to the collection of data in terms of privacy, choice of material to be included and acknowledgement of the difficulties perhaps experienced by participants or staff working with them. This idea of representation, allowing yourself as a researcher to be a crucial and empowering part of the research process is neatly in line with feminist theory and research. Feminist approaches do not stipulate one methodological approach but that the epistemological and ontological positioning of the research guide the way in which data is effectively collected. Stake's method of using Case Study as a methodological approach to qualitative research not only allows for this positioning to be upheld as identified in the introductory chapter to this study but Stake himself has also been described as "constructivist" in his approach (Boblin, 2013) particularly in his description of the involved and often prolonged role of the researcher themselves. This means that Stake (1995) unlike Yin (to be discussed) allows and embraces the bias and values that may be evident due to the ontological and epistemological positioning of the researcher themselves and the aim of the exploration of particular phenomena, hence the advocacy of Case Study research as a qualitative methodology. Case Study allows for multiple methods, but underpinning rules or suggestions on ethical ways in which to approach data collection and analysis is certainly reflective of the writing I have already outlined around why I have chosen to incorporate my methodology and then conduct analysis through a feminist lens.

In addition to Stake's views and writing, Yin is another influential and pioneering writer around Case Study methodology and research. More recently than Stake, Yin (2003) has gone on to outline clear procedures for data collection and analysis using this approach and suggested frameworks for choosing correct data methods as well as ensuring that research aims, and questions are clear enough to guide correct data collection and analysis. Yin's work has been particularly influential on my thinking as he discusses the need to provide information and background showing the processes for access to participants and introduction to the research field. However, the approach that Yin takes is perhaps more of a postpositivist one outlining the almost detached role that the researcher plays and the constraints and boundaries that must be followed within analysis of the unit of analysis which Yin uses to refer to the cases themselves, whether a group, organisation or individual (Yin, 2009). This has been particularly important so that I can effectively introduce the areas in which I conducted the research as well as the governance procedures both supporting and at times hindering my access to the participants and the clinical areas. Yin's practical suggestions which he terms his "Convergence of Evidence" have guided my decisions about which sources of evidence to use in gathering information ready for analysis as well as showing the importance of maintaining

chains of evidence while Stake (1995; 2005) is much more ontologically closer to my own way of approaching my research study.

I have referenced the above writing to demonstrate that there are both theoretical and practical elements of different Case Study authors which have led me to choose this as a methodology and to be able to justify this as a methodology in terms of how I will then outline my own data collection approaches and also approaches to analysis. I have also begun to outline the way in which I will approach this from an ontological position but now will also go on to discuss how this practically affects the design and application of my research study.

# 3.3.2 Case Study as the research design

Taylor and Gregory (2015) also help to define Case Study as a methodology in that they urge the researcher to fully understand and appreciate the subtle differences between this approach and other similar approaches. Their first discussion is around context. In this case, there is little room for doubt as to the context of my own research study. This includes settings which can form part of the case and which have been carefully selected and laid out as part of the formal ethical process and application but also the focus of what is going to be discussed first and foremost within these settings and with each of the participants. Due to my research questions and aims, the setting is key to the nature of this study. When Yin (2014) discusses defining the case he also discusses context but that this more hazy concept, while lending itself still to Case Study methodology, is also needing to be more rigorously defined to determine the unit of analysis. This allows for the researcher to construct clearer boundaries while considering the wider principles of Case Study research as considered by Taylor and Thomas-Gregory (2015).

Taylor and Thomas-Gregory's second point highlights the importance of the holistic approach. Here is where Case Study may possibly vary from some other methodologies in that a variety of methods are invariably employed in order to reach the required goal. Im's work (2010) allows for this point to reconnect my own study with its overarching feminist paradigm; namely the importance of triangulation and use of mixed methods for feminist researchers in order to reach a particular goal or to reflect particular intellectual or emotional commitments (Robson, 2015). It is that the researcher has at the disposal a means to adapt data collection or data analysis and these can be combined at will to suit the requirements of that particular case and the needs of the researcher in order to fully achieve the aims of their study. As long as focus remains on what is to be achieved, this often being the ability to present the voices of the women and these differences acknowledged

within the analysis phase, then this is certainly beneficial to my own research study. I am seeking to find out what experiences these particular women have had through the lens of seclusion as an often-silent minority within the inpatient setting. This is explored more fully within the literature review chapter and the literature pertaining to women with a learning disability in particular. Both Yin (2014) and Simons (2009) discuss how defining the approach to Case Study that a researcher may wish to adopt for their own study should also be guided by the existing literature on that particular subject or context. This then would lead a researcher to decide whether in depth interviews, more quantitative supportive data or demographic information is required to produce new knowledge. Yin (2009) emphasies that a less focussed and robust research question will potentially cause confusion or indecision when looking at what constitutes a particular unit of analysis and all choices made much aim to answer that question.

Referring back to my own research aims and questions I am aiming to explore the experiences of women with learning disabilities in secure care in the UK through the lens of seclusion. As a reminder those aims are shown below:

- Inform and contribute to the current policy drive / debate regarding the use of restrictive practices across mental health and learning disability services.
- Create service user informed non prescriptive recommnedations regarding the application of seclusion in secure settlings
- Contribute to service user informed training on the use of seclusion
- Capture the unique experiences of women who also have the diagnosis of learning disability by relating their own accounts.

I want to know these women experience and how they feel about using seclusion or being placed into seclusion. Literature outlined within the literature review chapter has concentrated on the gendered nature of services and a feminist paradigm adopted in order to try and ascertain the quality and "true" nature of this literature within the wider discussion around seclusion and secure services for people with learning disabilities. Few, if any pieces of literature concentrate on women as a unique group or attempt to capture the voices of women as individuals, although some small studies do often apply some of this approach when using qualitative methods to obtain data, e.g. Williams et al. (2018). Other literature that was consulted in order to consider the use of seclusion in particular tends to use gender within analysis around demography and staff practices and attitudes (Happell, 2011). The tendency is to consider women as a group of similarly presenting individuals. I want to explore some of their personal narrative, and Case Study, as discussed with

Taylor and Thomas-Gregory (2015) yet the research will be more applicable if it is to be considered in line and context with the existing literature and to be able to contribute to what is known about the female experience within secure services within the UK (Stake, 2005)

The decision is that the small groups of women detained in a secure hospital setting across the UK will form the unit of analysis. Nuances in care within a particular ward environment as well as the set up of each ward and its seclusion processes pertaining to the physical environment in particular will be acknowledged. The women themselves form the units of analysis and they will be provided with their own pseudonyms they have chosen themselves thus aligning further with the feminist principle of making the researcher / participant relationship more equal and their interviews and information pertaining to each person will be presented individually further on in the chapter. However, the mode of analysis and adherence to the qualitative methodological principles including chosen will allow for comparison and transferability across the host sites themselves and using the literature and consideration of the current discourse around seclusion and the female experience within a hospital setting

Case Study as a methodological framework also allows for a holistic approach to the research and treating each person as an individual, acknowledging their particular needs was vital to stay true to my own ontological positionality also. A "one size fits all" approach was certainly not going to work in this study, particularly during early interviews when both interviewer and interviewee were still getting to know each other. The research design was iterative and involved multiple interaction, during which time the best ways of speaking and interacting with each person were established. This allowed the consideration of potentially sensitive topics, again aligning with the feminist approach and gender nuances within seclusion experiences. The researcher's commitment to cultivating a good rapport with the interviewee on an individual level as well as promoting reciprocity and breaking down hierarchy are certainly important facets of feminist research (Oakley, 2016). Case Study allows this by ensuring that multiple sources of data allow me to take a reflexive approach inclusive of one's own observations, reflective discussions with others and analysis of written documentation also, considering their source and aim (Stake, 1995).

Reflexivity, key within feminist research as well as other methodological frameworks allows me to tackle any problems that may arise when the accounts of the women may either differ or when they may potentially view their accounts or voices as being particularly important themselves. This important skill of reflection in writing will seek to minimise any bias based on my own feminist perspectives as outlined in writings by Reinharz and Chase (2002) and Anderson et al. (1987; 2019) who discussed the concept of "false consciousness" in participants whose views of the world were

not in line with the researcher's own. It is important that this does not happen when I analyse the words of these women and that their "truth" should be treated as such. Houghton et al. (2012) along with Stake (1995) advocate the use of peer debriefing in order to provide robustness, in this case a part of the methodological approach which could include discussion with supporting clinical staff within the host sites and also my own supervisory team. This will nonetheless have to be balanced with the need to analyse and offer explanation for what the women are saying, and not simply a replication of words without meaning. Aspects of literature relating to intersectional feminism as well as disability studies (Goodley, 2017) also endorse this combining of social constructs and individual situations to provide a more robust and truthful presentation of the phenomenon being researched.

Case Study can be approached in a number of different ways however and models provided by Yin (2003) may suit some while others look to the baser reasons from an ethical perspective for adopting this approach with particular groups of individuals. Therefore Yin is not the Case Study approach I have chosen to align with in order to construct this study. Stake (1995) took the view that the approach will also depend on the epistemological stance taken by the researcher. Stake (1995) advocates for the interpretative approach which felt like a good approach for my study. Being interpretative means offering explanation when presenting the data. For example, this approach allows consideration and interpretation of many aspects relating to the individual being interviewed and their own unique experiences within the wider Case Study "site" yet also means that I have looked to construct or interpret social and even political meaning that may be shared between the different women and their experiences. This included information relating to the use of seclusion within the hospital more widely or even treatment approaches that are used to support them. This in turn will allow for the possibility of theory building. Cresswell (2007) highlights that while this approach does allow for the researcher to become part of the research to some extent that it may also neglect past and / or historical context, therefore meaning that it is important to understand that some of the experiences related to me may reflect past practices which are no longer relevant. However, by ontologically acknowledging my own background and knowledge around the women being interviewed and the services in which they are cared for from the beginning and allowing this to guide some of the interview questions and styles then this supported in redressing this balance. Incorporating historical data to some extent as part of the multiple methods of collection may also serve to address this potential issue.

One comment that is made by Crowe et al. (2011) is that should Case Study appear to lack rigour or maybe not always align to the chosen theoretical framework then the researcher needs to mitigate

this by taking various steps. One is to be rigorous in establishing epistemological position throughout and to reflect. These steps will therefore allow flexibility and for the researcher to be able to justify the use of some methods which may at times not perfectly fit into their chosen framework such as the use of some use of quantitative data to support or to test some initial findings. Within my study I used social circumstances reports to ascertain incidences of seclusion for each of the women over a period of time to gain some insight into whether women used seclusion more or less frequently over time in hospital. While Case Study welcomes the triangulation and complimenting of methods, it may be that the approaches used do not always sit traditionally within chosen frameworks. However, my framework allows me to reflect on these challenges and to shift the balance when interviewing and initial meetings with the women through the use of a very personal and holistic approach. Equally, my own epistemological stance to this methodology which endorses being interpretative and knowing the services and women through use of my own background and nursing skills should hopefully help to mitigate any difficulties of this kind.

Case study allows for data to be gathered from a number of different sources and perhaps even in a variety of ways depending on the data being used and then for this to be triangulated and used to build a picture and a narrative of the experience that the researcher is trying to capture. As already outlined earlier in this chapter it is important that this study adopts a qualitative Case Study approach in order to fit with the ontological and epistemological stance of the researcher but also to enable the study to be conducted through the feminist lens and within the framework and paradigm of feminist approaches that were discussed within the opening chapter.

# **Methods**

# 3.4 Case Study and choosing the host sites and designing the study

Initially three host sites were chosen and approached for initial discussions. Two of these were NHS, one medium / low secure and one high secure. All were required to provide a service for women with a learning disability and to have seclusion available within the setting and for the women participating to have used seclusion, if not at that hospital, at a previous placement. The third site was medium / low secure and was non-NHS provision. The three sites were spread across England. Initial discussions with the high secure hospital went well in terms of establishing a clinical link at the hospital and having discussions and a meeting with the NHS trust research department. However,

the two struggled to communicate with each other and time went by without progress in providing me with the necessary support and paperwork to enter and work in the hospital. Another potential issue at the high secure facility was that the service for women was not exclusively for those with a learning disability and conversations with a senior manager indicated that the definition of learning disability was understood differently and rejected in some cases despite it being known that a group of women had difficulty relating to understanding, communication, social interaction and sensory processing. Following successful relationships being formed at the other two sites, both medium and low secure with clear comparative ward environments it was decided not to include the high secure host site, although it was included in the initial ethics application. This also supported me as the researcher who would need to be realistic in terms of timeline for data gathering.

Table 2 Overview of the Host Sites and selection criteria met by each one

Selection Criteria met	Host Site 1	Host Site 2
NHS / Private / Independent / Voluntary Sector	Independent	NHS
Services provided for women with learning disabilities available to researcher	YES – Medium and low secure	YES – Low secure
Seclusion used within the host site and service	YES	YES
Support from clinical staff available to the researcher	YES	YES initially but then this was rescinded prior to data collection beginning

# 3.4.1 Sampling and recruitment

'Opportunistic, emergent sampling takes advantage of whatever unfolds as it unfolds' by utilising 'the option of adding to a sample to take advantage of unforeseen opportunities after fieldwork has begun' (Patton, 2002, p. 240).

While the sampling I chose was purposeful and participants were required to meet the criteria set out in order to participate in the study, timings, fluctuations in health and ability to consent and the nature of the services often meant that those available and able to participate at the right time and date were those that were then included in the study. The lack of insider status I held also meant that I was often unable to influence any guarantee of participation and had limited access to the women in their hospital setting at various times. (Suri, 2011). However, this approach also allowed me to be flexible and creative in the way in which I recruited. It also allowed me the opportunity to

capitalise on the situation in order to generate rich data in line with the participant number limit set within ethical considerations.

Fifteen individuals were interviewed as part of the study and data collection. Purposive sampling was chosen as the means to identify and recruit participants. This meant that the selection of participants would not be random but strategic based on identified inclusion and exclusion criteria which each participant should meet (Bryman, 2008). Braun and Clarke (2013) echo this definition of purposive sampling but also go on to say that the use of purposive sampling and ensuring that those interviewed will be able to relate experiences aimed at answering the research question then this makes the data richer (Braun and Clarke, 2013). The women recruited for this study as part of a purposive sample means that each participant should be female, have an identified learning disability, have had an experience of seclusion either at the current hospital placement or previously and be deemed to have capacity to consent to be interviewed by the researcher through assessment pertaining to the Mental Capacity Act (2005). This is important to ensure that the research question and aims remain focus but also that data and findings are able to then contribute more meaningfully to practice. It was also made clear that women would not be interviewed while actually in the seclusion room or within long-term segregation and that this would be based on their recall of using seclusion. Ethically it would not be appropriate to interview the women while so unwell and therefore perhaps with fluctuating capacity at that time. It was important not to interfere in any immediate treatment or assessment that might be happening as part of the seclusion process. A local contact at each of the host sites was identified to initially identify and in the case of Host Site 2 approach the women and obtain consent up to 24 hours prior to possible interview.

#### 3.4.2 Consent and sharing of information

When documents were being prepared for the ethics application, both via the HRA, NHS and the university, it was important to include the consent form and patient Information sheet being used. Again, the role of the researcher and their background was essential to a successful ethics application and approval due to being able to apply skills relating to communicating and understanding the needs of people with a learning disability. A consent form, GDPR and Patient Information sheet were designed based on this knowledge (see Appendices 1,2 & 3). The research department at Host Site 2 were able to support with a template that used simple language, pictorial aids approved by the Department of Health (2010) and then piloted its use on a group of women who may form part of the study. The women offered feedback on how easy the consent form was

to use, to understand and to follow. Following this feedback, colours, layout and language was further adapted and this became the template used for all subsequent interviews. However, the way in which the consent form and the research was explained was adapted on an individual basis when meeting each woman for the first time. In addition, guidance had been provided by the university and also the Health Research Authority suggesting best practice in terms of the length of time between seeking consent, gaining consent and then conducting the interview, allowing for the participant to reconsider and withdraw if necessary. However, the work around ensuring appropriate communication and understanding often meant that leaving the interview for a period of weeks in between often meant that the women had forgotten the details of the study and the process had to be repeated or they simply withdrew consent if they were not feeling too well on the day scheduled for the interview. On the advice of the research management team at Host Site 2 and the experiences I had at Host Site 1 when too much time elapsed in between completing the consent form and beginning the interview, the consent form began to be introduced as part of the interview itself or by the clinical staff prior to me arriving. Their knowledge of the women also meant that they were well placed to assess understanding levels of the women on any given day. While I did spend time at each site and on each ward prior to the interviews happening so that the women could meet me and I could introduce the study to them, their levels of engagement and attention were limited and sometimes it was therefore important to complete the consent form separately. Using Case Study as a methodological framework also meant that I needed to ask the women for permission to record them and also to be allowed to read any written material relating to them and their treatment and care. The consent form outlined all of this information.

In addition to this, in 2018 following ethical approval being granted, the Data Protection Act (2018) was enacted and laws changed relating to the use and storage of personal data. At this point I also had to design a form explaining this and how I would use and store data to the women themselves. The form provided to me by the university was insufficient as it was too complex. Once again I created an easy-read version of the information using pictorial aids and this was again piloted with a group of female service users at Host Site 2. Their feedback was useful but also demonstrated a lack of understanding of the legal and mandatory nature of the new law. This was fed back to the research management team at the site and also highlighted some useful learning in relation to research and ethics in these kinds of settings.

#### 3.4.3 Further ethical considerations

The study was granted approval by West Midlands – Coventry and Warwickshire Research Ethics Committee (REC reference 16/WM/0401) and approved by the Health Research Authority in March 2017. I obtained a Research Passport once individual site Research and Development Units had also approved the study and granted access (Appendix 4).

It was decided that semi-structured interviews would be the primary source of the data collection period approved, however, within this application and subsequent ethics committee reviews, it was also important not only to provide a timeline (down to the number of hours each participant would be required to engage in the study for) but also to carefully outline methodological approach so that significant ethical questions relating to issues such as safeguarding, disclosure, risk to the researcher and to the participants were answered. How would the researcher ensure that everyone involved would be fully supported, protected and what procedures would need to be put in place to ensure that risk was mitigated as far as possible? This is why epistemological and research paradigm were so important to identify early on in the research journey. Allowing time to explore the role that the researcher would play and identifying the importance of the role of the researcher as a learning disability professional allowed for particular questions to be answered satisfactorily and therefore for the research to proceed.

A feminist position also informed what I would do should I encounter any potential safeguarding issues that may in fact prevent effective data collection or by default even disempower the participant then I could prevent this from happening due to my adapting skills as a learning disability nurse (Burgess-Proctor, 2015). In addition to the role of reflexivity being mindful of potential patriarchal, traditional discourses also supported the robustness of feminism as an overarching paradigm to my methodology and methods. This in turn is vital for allowing knowledge to be produced that can then hopefully be applied or used within the nursing environment. Stanley and Wise (1990) while not discussing any particular context mention that analysis within feminist research centres on the "explication of the 'intellectual autobiography' of the feminist researcher" (p.209). Letherby (2003) goes on to suggest that data collected may be complex in nature, either by its content or the way it is presented and the ability to consider this from the viewpoint of the individual is invaluable.

Burgess-Proctor (2015) raises the difficulty of processes and protocols within the negotiation of the ethical questions of research and designing a study which is true to its aim and stays true to the researcher's epistemological and ontological positioning. This may include processes such as

requiring an alarm, keys, someone to be with me for safety during interview. All of which could position me as a member of staff in the eyes of the participant. It may be argued that any conflict arising from such processes and protocols designed to protect individuals may be by default traditionalist and positivist in their approach, thereby being in direct conflict with the aims and methodological approaches of the research or even getting in the way of conducting research if the data collection process should have to be abandoned or halted at any point. Burgess-Proctor goes so far as to say that "safeguards may actually reinforce disempowerment" (2014: 75). She then suggests ways in which the researcher might challenge and begin to overcome this potential problem. One is reflexivity. Another is the ethic of care, worth mentioning as this is directly aligned to my epistemological stance using my own nursing background. At the heart of the research is the desire to show respect, ensure everyone is safe and not distressed by the research process in any way.

## 3.4.4 Adjusting the design – unforeseen circumstances

Doctoral standards based on and outlined by Wellington (2013) discuss the need to adjust the design of research studies if there are unforeseen circumstances. Within health care there are often issues associated with what is sometimes referred to as gatekeeping or bureaucracy. This gatekeeping often serves a political agenda but can also serve to restrict access in the interests of patient care and confidentiality (Brekke et al. 2007). Governance and data protection are also inextricably linked. While I was preparing to go into Host Site 2 I was informed that I would no longer be allowed to access any written data about the women which had been approved ethically and had been considered within my methodological design using Case Study approach as outlined earlier in this chapter. I was also further denied the opportunity to speak with staff about the women that I was interviewing. An amendment had been sought via the ethics committee to outline further the specific nature of any documentation being accessed and was granted but the reasons I was given related to consent and that the hospital felt the women were unable to give informed consent to me accessing their written care notes. I therefore made the decision to use the interview data as an additional source of data that could support the coding and theming from the data and triangulation already conducted at Host Site 1. Therefore interview data from Host Site 2 was further triangulated with the analysis from Host Site 1 along with my observations and anecdotal information relating to Host Site 2. What I did not want to do was to ignore the data from my interviews at Host Site 2. What these women would had to say was too important and they had given their consent and time to meet and speak with me. I also did not want to lose the integrity of the research so considered

more carefully how the interview data would be used and analysed robustly without the additional data from the site to support it.

#### 3.5 Data Collection

## 3.5.1 Giving the women a voice

My literature chapter outlined the development of female services for women mentally disordered offenders. As shown, much of the literature pertaining to females generally is then transferrable, at least historically, to the female with a learning disability (Somers and Bartlett, 2014; Nicholls, 2009). It is only recently that services have begun to tailor more towards the needs of individual with a learning disability and / or autism and within this, gender is now more carefully considered in regards to treatment approaches (Thomson, 2012). However, as shown, much of the evidence highlighting concerns or treatment using seclusion and associated physical interventions do not tend to explore and therefore show phenomenological differences pertaining to gender or even people with additional cognitive disabilities (Happell, 2011). My introduction has set out the aims of this study and then gone on to discuss the existing evidence and literature relating to the subject and the participant group to date. This in turn leads us to explore the methodological approach chosen to undertake this study. It is important that staying focussed on methodology allowed for all ethical considerations to be accounted for and therefore enabling the researcher to remain consistent in approach and allow for rigorous and detailed analysis of the narrative.

Margaret Lloyd (2001: 716) commented that "the problems experienced by disabled women can be seen to be as much on account of their gender as their disability". This seems to suggest that we therefore need to embrace research on these women underneath the umbrella of feminism. However, this comment is also slightly at odds with some of the more outdated models of feminist research approaches (Hammersley, 1994), that is to say that we *do* need to consider the disability and uniqueness as well as gender. These women deserve to be "researched" from all angles essentially. They cannot be compared according to traditional roles of women within society, yet are automatically disadvantaged because they are women (Buker, 1990; Garland-Thomson, 2017). This is supported by Maynard in an earlier discussion (1994) who mentions the importance of acknowledging all additional parts that make up a person's unique experience. Maynard includes race, gender and disability within this discussion. The discussion also highlights the need to relate experiences and to join the dots of these different and unique narratives otherwise, while important to the idea of "truth" and individualism, it also can mean fragmentation within the analysis stage.

This would mean that having a study which could then go on to potentially inform future practice or even policy would not be possible.

Giving the female participants a voice within this study and not simply repeating what they said was tackled through understanding and consideration of ethical issues. Understanding the background of these women and their experiences relating to historical and ongoing trauma meant that this would be carefully thought about when designing the data gathering approach. It was important that their experiences related could be gathered and interpreted within the knowledge that they sat within services which they may feel have failed them, that often prevented them from doing what they wanted to do and that they felt may even punish them for displaying behaviours that they felt unable to control or even understand (Fish and Duperouzel, 2012). This is where the consideration of gender is important to the methodological paradigm or framework adopted. As discussed in the literature review, women's services were historically developed amongst how they differed or contrasted to their male counterparts and therefore at times adapted, or even seen as more difficult to manage due to this focus on difference and comparison (Somers and Bartlett, 2014; Long, 2012). Feminist research principles have allowed for this group of women to be considered carefully within their unique and perhaps even oppressive environment but also guide the way in which data is collected and then used.

## 3.5.2 Designing the interview questions

Semi-structured interviews were felt to be the best method to collect data directly from the participants. This method allowed for time to be spent with an individual and that a general template of the interview outline and aims would allow the researcher to develop initial rapport and to help prepare the participants during initial meetings. However, the lack of rigidity and the flexibility of questioning style meant that the research could stay true to ontological and person-centred beliefs and allow for each participant to be questioned in a way that might work best for them, for example, allowing their response rates and answering style to guide the next question (this may include responding directly to distress or becoming more animated over particular questions) and to ask each question in a way that felt appropriate to that interview. Staying true to epistemological positioning and the feminist framework being utilised to practically conduct the study also meant that the researcher could engage slightly off topic where necessary as well. This was aimed at gaining confidence and appearing human and non-threatening to the participant if more personal questions were asked of the researcher. It is part of the aim of rejecting that

traditional hierarchical relationship in research and allowing the women to guide the research process more themselves (Kelly et al. 1994). Further examples of this will be referred to when presenting the case studies and discussion around the interviews themselves.

Questions were developed that were open in the sense that the first question allowed that individual story to come through. So for example, a question to open the interview would be worded something like "tell me about the seclusion room?" or "what is seclusion like?". These are short and open but allowed the woman to begin to tell me their story. They were also short so that the women were not overwhelmed by unnecessary words they would struggle to process or understand. However, if the answer was short and did not provide much information then I would follow this up with more closed questions, asking about the features of the room, why was the woman usually put in seclusion or how they feel when in there and why.

Finlay and Antaki (2012) conducted a study looking at adapting question styles for people with a learning disability in order to elicit and generate more meaningful data while simultaneously mentioning the pitfalls of over simplifying questioning or undue direction. They acknowledge that poor questioning and interviewing styles without sufficient preparation can in fact cause undue distress for the person being interviewed. It then goes on to highlight good practice, showing examples of using repetition effectively, rephrasing and reformatting and also using body language and gestures where needed to support questions. This was certainly something I did within the interviews, trying to mirror language used by the women to show that I understood them and using key words rather than long sentences. What was fascinating about this study by Finlay and Antaki (2012) is that it clearly showed the level of skill and also understanding of that individual that was required to not only elicit a response but also to promote choice and understanding. As already shown in the introductory chapter, this research study ontologically and epistemologically has aligned itself to a framework that wants to promote those exact values but also in doing so acknowledge the importance of the skill of the researcher. Other work exploring qualitative research and people with expressive language difficulties (Lloyd et al. 2006) highlights that conducting an interviewed aimed at allowing people to provide their own narrative and experience is important to allowing people, often previously excluded or ignored within research to have a voice. Like Finlay and Antaki (2012), authors such as Lloyd et al. (2006) and Gillies (2000) emphasise that not taking what someone says explicitly as important or overlooking their own personal response is to further marginalise them. It was therefore important in my study to follow up any answers that were perhaps a little short in narrative from the women or vague or perhaps even slightly apart from the question I had asked. Within this study it was therefore important that the interview data be viewed as the main source of data and that additional sources as identified through the Case Study methodological approach were able to form triangulation (Stake, 1995), validation and support continuing analysis and reflection.

Outlining Case Study at the beginning of this chapter and its appropriateness to the research study being undertaken, has shown also that reliance on the skill and knowledge of other staff within these host sites being used will also form part of the data gathering and analysis process.

Therefore using a qualitative approach to Case Study research means that I would be using data based on the following sources:

- Semi-structured interviews with the participants (women from Host Site 1 and 2).
- Observations made by me as the researcher during interactions with the women and staff
  on the wards notes were made, reflections collected and analysed within the triangulation
  approach (see Appendix 5)
- Information written within reports outlining the women and their progress in hospital –
  these were in the form of social circumstances reports and mental health tribunal prepared
  reports from Host Site 1. This was approached thematically and applied through
  triangulation with the interview analysed data. They also provided more knowledge of the
  women, their clinical diagnosis as well as their seclusion and mental health related history.
- Informal discussions with supporting clinical staff at the hospital. These will be used to reflect and confirm details following the interviews with the women

## **Triangulation**

Yin (2009) discusses his Convergence of Evidence model as being ultimately the way varying sources of data are analysed in order to produce fact. However, Stake (1995) along with Houghton et al. (2012) focus their approaches to Case Study research as being interpretive and the robustness is sought in the planning inclusive of the relationships and trust built with participants and in this case Host Sites. Boundaries must be established, and ethical considerations identified as much as the ways in which data will be gathered and stored. Stake in his checklist (1995) demonstrates that validation is sought by also establishing the need to triangulate. Triangulation is an important part of this study and this was discussed with each host site prior to data collection commencing and the ways in which this would be done were discussed. Stake did not simply mean that triangulation meant cross-referencing data but within the more qualitative approach, triangulation meant to ask "do I have this right?" (Stake, 1995: 107). Triangulating the interview data with observations, reflections on those and the written information relating to the women and their treatment in

hospital meant that I sought to validate my findings but also questioned more robustly whether what I was thinking was in fact really representative of the women and their experiences. Stake (1995) also mentions that triangulation may also invalidate what we are beginning to interpret in our findings. If we also tend to believe in the validity of a social construct then this may be far more challenging as we cannot simply rely on another's own interpretation to validate our own or to carry out a similar check in the same methodological way (Denzin, 1993). However, if we are comfortable on including additional interpretations and reflecting on those in our research and allowing them to support our work rather than aiming to confirm a single meaning then triangulation can still be useful.

# 3.5.3 Consideration of learning disability and interviewing technique

Kiernan (1999) discusses how by its very nature, and speaking generally, government funded enquiry or research is not emancipatory, and may not even be entirely participatory. However, a critique of one's own research is highlighted as powerful in moving research with people with disability / LD beyond what has previously occurred. Walmsley (2004) offers examples where researchers have reflected and almost bemoaned their own efforts to get it right, enable full participation or even embrace emancipatory research. Walmsley interestingly identifies the power of language and also how language can confuse by blurring what roles are actually carried out through the interchangeable and varied use of language. For example, referring to myself as "enquirer" and the women as "expert" (Knox, 2000) would appear at first glance to at least make some attempt to reverse traditional roles and to challenge the hierarchy (the feminist paradigm) but has this really happened? Ultimately interviews are conducted with an agenda and with the intellectual knowledge coming from myself and staff involved in supporting the research process. Therefore clarity is key, acknowledgement of the limitations in at least trying honestly to include the women in the process. This will be shown through a number of techniques, linked to the feminist framework chosen and the methodological approaches. Therefore, the choice to present each woman as their own case, rather than just a collection of voices is important. Detailed discussion on how we conducted the interview, the adaptations made to check and re check information will be presented. As the commitment is to finding out just a little bit more and making sure that I fully understand what each person is saying. This was done in a variety of ways. For example, the going back to check information. The triangulation of data with what we already know about the women, their lives and communication is another way to demonstrate this commitment. In addition, reflexive

accounts of the interactions with each woman, and my own conduct within the interview provided further insight into the desire to really include and involve these women in this research.

When thinking about how I would approach and conduct each interview it was important that I was consistent but not necessarily offering the exact same experience to each woman as I was considerate of different personalities and the fact that the women may view me differently dependent on their own viewpoints and experiences. I wanted to allow them to feel that they could also ask me some questions in order for them to feel more comfortable or to better understand my motivations behind asking them certain questions. McCarthy (1998) discusses her experiences of interviewing women with learning disabilities and her own feminist research. She relates experiences of allowing the women to ask her any personal questions if she is comfortable to answer as she believes this may support in them working out their relationship to her, particularly in relation to gender. I was prepared to consider this within my own interview experiences, however also being mindful of my professional situation also. Would the women embrace me into the culture and confide in me if they thought of me as a nurse or would this stifle their responses? This was also with thoughts about how staff and patient experiences of seclusion and restrictive practices had often been shown to be at odds with each other in previous research (Meehan, 2004). I was particularly conscious of the need to at the very least challenge any perceived hierarchy of power. For this study this would manifest itself in a range of choices relating to the interviews with the women, some of them more subtle than others. Following introductions to the site and ward areas and initial discussions with the supporting clinical and research staff about the women I decided to ensure the following points were considered:

- Willing to acknowledge and answer questions relating to my own personal circumstances and to give the women the opportunity to ask me anything additional following the interview
- Acknowledge myself as a learning disability nurse if that felt appropriate when introducing myself to the women
- Conduct the interviews in settings that felt comfortable and safe to the women and to allow these interviews to be conducted with others in the room if that was what the women preferred
- Not insist on audio recording if the women did not want this to happen
- Not to hold keys as the staff employed on the ward did but to be equipped with an alarm if that was required by the hospital for my own safety

• I would be forthcoming about any issues relating to confidentiality. This would be explained as part of the consent process

It was also important that I consider whether I would always interview the women on their own or more than one at a time. The women would therefore be able to make this choice if it meant they felt safer or more comfortable during the interview. I decided that staff could be present if chosen by the women. Wilkinson (1998) discusses the benefits as well as some of the potential difficulties in conducting focus groups in order to promote a sense of empowerment. Wilkinson argues that from a feminist perspective the focus will allow a shift in power and to enable the participant's own social context to thrive and that this risks being eroded by the one to one interview. She argues that for some research, the semi-structured nature of the group interview supports free discussion not bound by the agenda of the researcher. For this study I made the decision not to conduct focus groups due to not being entirely sure of the dynamics between participants or the ability of all to speak up without significant support. As Barr et al. (2003) recount, focus groups have been used successfully in a number of studies with people with learning disabilities, but there can be problems. These include problems with communications, histories between the group participants and the risk that those who articulate less well may be left out from the group. As the researcher who does not know these women well already, I felt that it was more important that I was able to spend time with each individual. However, with regards to the interviews themselves I am also mindful of what Goodley (1998) commented on which was the need to not treat people with learning disabilities as a homogenous group and to adapt. Therefore, if any of the women wanted to be with each other during the interview then they could be and I would be guided by each woman as to how they wanted interviews to take place.

#### 3.5.4 Meeting the women

Appendix 5 provides more detail through reflective discussion around the Host Sites and my introduction to them, the ward areas and the women themselves inclusive of interview experiences and challenges. However, before I end this chapter with an overview of how the thematic analysis model described previously was then applied and utilised within my study, I want to introduce the participants whose narratives and experiences I am aiming to relate within this thesis. They are so integral to understanding the concept of seclusion within their unique population that I felt to consign them entirely to an appendix was not correct.

#### Some common features

In presenting the case studies as a group profile, combining the interviewees from Wards A and B from Host Site 1 I was able to capture some of the individual stories and features from each participant. What was useful was also having access to clinical reports relating to each woman that I interviewed. These revealed other trends, both in the women's histories, diagnoses and their responses to treatment approaches. One such example is the frequency with which the women had moved from one service in the UK to another, often a long way from family or where they had originated from. Tee was just 19 at the time of the interview but had already had more than six different placements either at different hospitals or moving across different wards within hospital sites. Jay, in her late 30s at the time of interview had had around 20 different admissions to various units and services as well as also spending time in prison. At Host Site 2 I was not permitted access to this information, but women confirmed multiple placements during the course of their interviews, for example, both Julie and Natalie describe their seclusion experiences at both current and previous placements interchangeably.

# Names and confidentiality

The women's real names are not used within this study write up. I alternated between finding my own coded name for my own data analysis use so that I would better recognise and connect with the person I was writing about and asking the women what they would like to be referred to as. Some did choose a name but others either struggled to identify as anything other than their own name or nickname or either they did not want to do this and weren't bothered. Some women would shrug and say, "don't care, you pick". The names shown below therefore and the write up are either the names the women chose or is the name I gave them.

## Forensic history / offending behaviour

While offending history was not discussed explicitly within the women as part of the interview process it is part of their history and their experiences. I therefore chose to include it as part of each participant's profile at Host Site 1 where I had access to this information. My literature review was able to provide an overview of the offending profiles of women detained within these services and the gap in data often due to lack of prosecutions and proceedings against this population. It is interesting that were we to delve a little deeper into the types of treatment that the women receive, we would notice that treatment usually relates to the mental health diagnosis and other associated disorders, for example a focus on cognitive behaviour therapy approaches, emerging personality disorder treatment groups rather than offending behaviour in particular. This is often quite different

to what we read about approaches to treatment and male service approaches, for example, the use of the Risk Needs Responsivity model and Finkelhor model for treatment and sexual offending has not been applied to female services in the case of Tee for example. Similarly, we do not see the women here attending the same treatment programmes relating to arson (overrepresented in the female offending population) as their male counterparts (Taylor and Linday, 2010). More recent approaches to the care of people with learning disabilities highlight treatment work involving Dialectical Behavioural Therapy.

Below is the group profile of the women I met at Host Site 1 and 2.

Table 3 Group Profile from Host Site 1

Name	Age (at time of interview)	Diagnoses	Offending behaviour / history	Clinical presentation linked	Seclusion history / identified patterns	Personal background / family history
Tee	19	Attachment Disorder	History of Class C substance misuse	to diagnoses Self- harming behaviours		
		Autism Spectrum Disorder	No convictions	Physical and verbal aggression	Secluded due to physical	Behaviour documented often refers to past traumatic events
		Mild Learning Disability (IQ-52)	Inappropriate sexual activity and behaviour in public and with minors	Social and emotional difficulties in communicating and forming relationships	aggression. Self-harm continues within the seclusion room resulting in being held physically within the seclusion room on multiple occasions	relating to being female and relating to sexual abuse and trauma. Non substantiated in early history
				Difficulties with emotional regulation Encopresis		Family history of mental health issues and
				Seizure activity possibly linked to form of self-harm		
				Gastroenterology complications		
Sweet	19	Emotionally Unstable Personality Disorder	No convictions	Self- harming behaviours	Seclusion usually used to manage severe episodes of self-harm	Reports of past sexual abuse and rape not substantiated by early reports.
		Generalised Anxiety Disorder		Absconding from hospital		Affected by father's death.
		Mild Learning Disability		Talking of wishing to die		Likes to write poetry
				Physical aggression towards self and others		
				Gastroenterology complications		
				Impulsivity		
				Reported auditory and visual hallucinations		
				Allegations towards staff of physical and sexual assault		

				T		1
Jay	38	Emotionally Unstable Personality Disorder  Mild Learning Disability	No record of formal forensic history but reports of incidents requiring police intervention	Auditory hallucinations Recurrent flashbacks	Repeated episodes of seclusion often recorded as due to attempts to harm others – usually staff	History of alcohol and drug misuse Childhood trauma relating to kidnap
				Aggressive and physically violent behaviour towards self and others.		A mother
				Speech impediment due to corrective surgery		
				Sexually inappropriate behaviour		
				Seizure like episodes which may also be attributed to Transient Ischaemic Attack (TIA) but not proven with investigation		
Сар	27	Emotionally Unstable Personality Disorder	Extensive – between 20 and 30 convictions including damaging property, arson, common assault and battery and breach of ASBO	Self-injurious behaviours	Repeated short episodes of seclusion usually related to physical assault on others – usually peers	Self-reported episodes of sexual abuse from childhood.
		Mild Learning Disability	Time spent in both prison and hospital settings	Aggressive and threatening behaviour – verbally and physically		Documented difficulties in relationships with family members when young
		Hyperkinetic Disorder		Physical side effects from anti- psychotic medication including hypersalivation and slurred speech		History of alcohol and drug misuse
				Auditory hallucinations		

Celia	22	Emotionally Unstable Personality Disorder Mild Learning Disability Hyperkinetic disorders	Multiple assault charges One conviction for assault	Self-harm  Physical assaults on staff  Verbal threats to kill  Inappropriate sexual behaviour towards staff	Seclusion episodes often relating to risk around self-harm and subsequent assaults on staff often for more than a day at a time	Difficulties with early childhood and attention difficulties at school
Beth	30	Mild Learning Disability Emotional Unstable Personality Disorder	Over 38 convicted offences and numerous non-convictions. Theft, public order and driving offences	Aggressive verbal and physical behaviour towards self and others History of psychotic symptoms Self-harm	Previous repeated shorter incidents of seclusion but this has begun to decline in frequency	A mother  History of alcohol misuse  Difficulty with personal relationships
Kate	41	Mild Learning Disability Emotionally Unstable Personality Disorder	Charges and convictions relating to assault, criminal damage, violent behaviour and theft	Self-harm  Aggressive and physically violent behaviour towards others  Deterioration of mental health when hospital transfers occurred	Periods of seclusion have reduced but when they occur linked to risk associated with self-harm and subsequent assaults on staff	Behaviour documented often refers to past traumatic events relating to being female and relating to sexual abuse and trauma. Non substantiated in early history
Tattoo		Emotionally Unstable Personality Disorder Mild Learning Disability	Extensive forensic history. 25 formal convictions including assault, public order offences, drug offences, minor road traffic offences and theft	Reports of psychotic symptoms previously Aggressive behaviour towards others  Incidences of numerous seizure like episodes which have been attributed to be non-epileptic and that Tattoo has control over  Self-harm	-	-

Table 4 Host Site 2 Group Profile – Women interviewed all between the ages of 18 and 65.

Name of Participant	Observations	Additional information provided by staff	Particular requirements during interview
Bee	-	-	Due to observation levels this interview was required to take place within eyesight of staff members.
Emma	Numerous scars on face indicating self-harm and confirmed within interview	-	Difficulty articulating speech, was sometimes difficult to interpret and hear what was being said during the interview. Emma was extremely patient with me during questioning.
Debbie	Physical evidence of self-harm around arms and face	Staff provided evidence during the interview around Debbie's levels of self-harm and the impact this has on using seclusion	Debbie requested a staff member to be with her during the interview
Georgia	Georgia presented with very poor personal hygiene and physical evidence of self-harm. She was withdrawn and difficult to engage at first.	-	-
Julie	-	Julie had previously participated in research taking place in the ward environment and seemed very comfortable with the process	-
Karen	-	Karen had also previously participated in research in the hospital and was comfortable and willing to talk	-
Natalie	Physical evidence of self-harm around face, arms and head. Again confirmed by interview and staff.	-	The interview disclosed a potential safeguarding concern. This was safely passed on following the interview.

I will now outline the key clinical staff at Host Site 1 that supported the triangulation effort within my data collection and then my data analysis both during and following interviews. I will provide them with a pseudonym and then show which host site they were aligned to, which role they fulfilled, both within the hospital and my research and the way in which their triangulating evidence was presented. All members of staff who contributed have given permission for our discussions to be reflected within this study.

## <u>Dr Sand – Consultant Psychiatrist and Responsible Clinician (RC)</u>

Dr Sand was instrumental in host site 1 in introducing me to all of the women who resided on both Ward A and Ward B. Dr Sand was the RC to all of the women across these two wards and medically trained. I was provided with an insight through lengthy discussions to each woman who offered me an interview and also provided in accordance with the ethical approval granted for the study with the opportunity to view a variety of reports, inclusive of mental health tribunal reports all written by Dr Sand.

Below is some of the interview data that was then triangulated with the clinical knowledge and opinion expressed by Dr Sand along with the other staff consulted and then considered within the generation of the main themes during thematic analysis.

#### <u>Joanne – social worker to many of the women interviewed at Host Site 1</u>

Joanne, like Dr Sand was extremely supportive, allowing me to reflect on how initial interviews were going with her and to discuss my initial thoughts. Joanne was also able to provide additional insight into the women including their histories, their habits and also the ways in which the may present and communicate and why this might be. One example was that Bethan appeared extremely articulate and also quite intimidating and dominant, both in appearance and the way she spoke to me. However, Joanne explained that Bethan had experienced a sense of injustice from time spent in her previous hospital placement where she had been moved due to a violent incident believed to have been initiated by other women. It appeared that Bethan masked her level of learning disability, appearing much more able than she perhaps was. While I was able to read this in her report provided by Dr Sand, Joanne was able to provide me with some examples and the way in which Bethan might answer a question, particularly if she did not understand it, so that you assumed she did understand. Joanne was also able to provide a staff perspective into some of the responses the women gave to me during interview. This was interesting as I certainly did not dismiss the feelings and interpretations of the women at all, but it did show that they did not necessarily always understand seclusion and the processes around it. For example, Celia reported to me that staff did not bother to talk to the women when they were put in seclusion. Joanne wondered if this was because if any of the women used the "quiet" room rather than being put in seclusion to calm down then they would have a member of staff in there with them. Was it possible therefore that Celia viewed the quiet room and the seclusion room as serving the same purpose as she did not appear to understand or know why staff did not go in to speak with her?

## Dr Fell

Dr Fell began working as a Consultant Psychiatrist and the RC across Host Site 1 wards in the years following the interviews. Once data analysis was underway I contacted Dr Fell to ask for some thoughts about my initial analysis itself and some of the initial codes from the interviews in 2018. This was interesting and also allowed me to feedback some initial findings to the hospital directly. For example, a number of the women had reported feeling cold in the seclusion room but did not think to ask for a blanket or for the heating to be turned up. I fed this back to Dr Fell as I had to Dr Sand some years previously.

## 3.5.5 Reflection in action

Reflective journaling was a key part of the data collection process. This reflected the feminist paradigm that I was using to conduct the study and also remaining true to the qualitative nature of the Case Study approach I was choosing to use. I kept written notes, both typed and hand written throughout my time conducting the research and gathering data. This is demonstrated through appendices but there is a short piece of reflection below which allowed me to focus on the way in which I was gathering the data and then considering how I would begin to interpret and analyse.

Teams call with Host Site 2 Research Manager – 28th Jan 2019

Women – identity e.g. Julie appears to have knowledge of herself and her consistent way of expressing. Natalie – unsure of who she is when discussing – how long would it take to know these women and understand their behaviours. Trauma informed care? How could I interview them without getting to know them first? What needs did they have for the interview process. Did convergence play a part when I adapt my style of speaking to them?

Feminist approach is adopting an individual approach to this particular study. We never quite got there sometimes with the inclusive nature of gathering data, it wasn't a reciprocal relationship.

See Appendix 5 for further examples of this approach.

#### 3.6 Data Analysis

### 3.6.1 Thematic Analysis

In order to defend the chosen methodological standpoint and framework overarching the research study, the research must choose data analysis methods which then align carefully back to the research lens applied within the literature review, methodology approach and then the data collection process (Bryman, 2008). Qualitative research does not always inherently lend itself to robustness and often requires this careful demonstration of alignment and transparency so that credibility of findings can be shown (Attride-Sterling, 2001; Nowell et al. 2017).

The previous sections have outlined the methodological approach of Case Study and the data collection methods employed to gather information relating to women with learning disabilities and experiences of seclusion. The interview data will be reflectively analysed in accordance with the feminist lens being employed throughout this study and this sub chapter will now begin to explore the choice of Thematic Analysis (Braun and Clarke, 2021) as the primary overarching method of data analysis. The discussion will begin with the choice of thematic analysis as the chosen model, why the choice of the particular approach to thematic analysis and then how each phase was applied to the data gathered. Within this discussion the concept of trustworthiness and truth will also feature as

additional concepts or features to support the approach to coding and theming are explored in relation to the transcription and the way in which data has been gathered and interpreted.

Thematic Analysis has been described as being flexible in its approach (King, 2004) that allows the researcher to adapt to suit their study and the people they are writing about. From the perspective of this study, the relative flexibility of thematic analysis as a general tool for data analysis can support a novice researcher and this can allow more in depth exploration of the surrounding methodological frameworks. This flexibility compared with more didactic approaches to data analysis could risk a misalignment with the desire to maintain a feminst approach although as we will be able to show, features of such approaches including Interpretative Phenomenological Analysis (IPA) will certainly contribute to more in depth coding within this particular study. Rather than wishing to adopt an approach such as IPA which is an identified methodological approach that also includes the analysis phase, it is felt that thematic analysis can be successfully integrated to the methodological approach identified through Case Study without the pre-conceived psychological assumptions that IPA may require (Smith and Osborn, 2008). Thematic analysis does not preclude a complex data set that also seeks to analyse the individual separately as well as part of the wider theming.

As already mentioned briefly thematic analysis can be supportive of the novice researcher, allowing the researcher to clearly define and then show the different points of thematic analysis. The researcher has chosen to employ Braun and Clarke's model (2021) which is shown in the table below but it is also important that this is shown to work within the context of both Case Study research and also sitting comfortably within the feminist framework overarching the whole study. While flexible and commonly used, thematic analysis is occasionally overlooked perhaps due to its application to numerous methodological approaches rather than its lack of citations and in comparison to other analysis approaches due to its lack of identity within one methodological approach such as IPA or coding within grounded theory as outlined by Glaser and Strauss (1968) and therefore its heritage is harder to show and therefore to appreciate.

Choosing thematic analysis as per Braun and Clarke (2021) also allowed for initial coding to be generated from what was anticipated to be limited written data from some of the interviews. Some of the women being interviewed, gleaned from initial discussions with clinical staff, social circumstances reports and psychiatric reports and the researcher's own knowledge and observations were unlikely to answer in long, detailed description. Their answers were likely to be short, to the point, even one word answers depending on how questions were asked. This had been previously shown within similar studies amongst those in secure settings with a learning disability (Fish, 2018;

Lovell, 2004; Johnson and Thomson, 2015). What Braun and Clarke stipulate is that generating initial codes is essentially the process of documenting interesting features of the data in a systematic way over the whole data set. This sits comfortably with the epistemological position outlined within the introductory chapter which firmly positions the researcher, with a degree of insider knowledge (Stake, cited in Boblin, 2013) and for them to experience the phenomenon as part of the research itself. Therefore, coding according to Braun and Clarke which means that interesting features as identified by the researcher are based partly on what is already deemed to be known and acknowledged about this particular area of research and the phenomenon being explored in particular, allowing the researcher to bring in their own observations, knowledge and interpretation to the analysis process. Nowell et al. (2017) go on to support this point when they use Braun and Clarke and apply particular criteria to the analysis process in order to try to establish trustworthiness and credibilty to their research. They seek to strengthen the position of thematic analysis within the analysis hierarchy and qualitative research. Within the coding phase as just outlined, they refer to researcher triangulation and reflexive journaling as ways in which to complete this phase of thematic analysis (2017). This fits well within the study being conducted here as the reflexive nature of the feminist framework overarching the research study, the reflective work that went on and was documented through regular supervision and journaling during this phase and beyond of analysis as well as the use of researcher observations as per Case Study research approach means that we can use Braun and Clarke, supported by the work done by Nowell et al. to provide support and a robust analysis framework to this study.

Table 5 showing the Braun and Clarke model of thematic analysis (2021)

Phase		Decription of the Process
1	Familiarising yourself with the dataset	This phase involves reading and re-reading the data, to become immersed and intimately familiar with its content, and making notes on your initial anlaytic observations and insights, both in relation to each individual data item (e.g. an interview transcript) and in relation to the entire dataset.
2	Coding	This phase involves generating succinct labels (codes!) that capture and evoke important features of the data that might be relevant to addressing the research question. It involves coding the entire dataset, with two or more rounds of coding, and

		after that, collating all relevant data extracts, together for later stages of analysis.
3	Generating initial themes	This phase involves examining the codes and collated data to begin to develop significant broader patterns of meaning (potential themes). It then involves collating data relevant to each candidate theme, so that you can work with the data and review the viability of each candidate theme.
4	Developing and reviewing themss	This phase involves checking the candidate themes against the coded data and the entire dataset, to determine that they tell a convincing story of the data, and one that addresses the research question. In this phase, themes are further developed, which sometimes involves them being split, combined, or discarded.
5	Refining, defining and naming themes	This phase involves developing a detailed analysis of each theme, working out the scope and focus of each theme, determining the "story" of each. It also involves deciding on an informative name for each theme.
6	Writing up	This final phase involves weaving together the analytic narrative and data extracts, and contextualising the analysis in relation to existing literature.

# 3.6.2 Inductive and Deductive Analysis

It is naïve to assume that the thematic analysis for this study could be an entirely inductive process. Inductive thematic analysis as set out by those such as Boyatzis (1998) demonstrate how the researcher would approach coding without pre-conceived ideas or concepts and lets the data speak entirely for itself. It could be argued that this would suppose that the data is taken at face value, without consideration about what may be contributing in terms of additional information about the participants or the knowledge already possessed about the environment and / or policies and procedures adopted by the hospital. However, not allowing new data to enter into the analysis phase would also be a possible rejection of the need to empower the women in this study to speak out and to show us if there is anything different that they might experience based on their gender or

their disability. It is also contrary to the Case Study methodological framework being applied to the study. Not employing an inductive process alone also supports the issue of the literature on this research topic being somewhat scarce in relation to both the female experience but also the experience of those with a learning disability. We need to incorporate as much of this information as possible to gain deeper insights. It is important to be able to reflect on data that may seem new or surprising based on what is already known. Therefore, inductive coding was certainly used but in combination with deductive coding. This approach is demonstrated by Fereday and Muir-Cochrane (2006) who demonstrate their own research using both inductive and deductive models of coding within thematic analysis. They seek to show rigour and faithfulness to the raw data, namely the words of their participants while also demonstrating rigour should there be gaps or limitations of that data, namely the deductive process. This viewpoint will be adopted within this study exploring the women at my host sites and their experiences of seclusion. It is anticipated based on previous experience within this service and the advice of others working within the sites themselves that the women may or may not be able to choose to do follow up interviews as outlined in the schedule of activities and within the IRAS ethics application and that this may make it more difficulty to analyse codes and to check meaning and understanding. Case Study, allowing multiple sources of data to provide richness, a wider perspective and richer data therefore endorses a deductive approach which also allows for the pre-conceived thoughts and knowledge of the researcher to be used where appropriate.

## 3.6.3 Analysing the data

Below demonstrates each step as per the Braun and Clarke 2021 model. This section provides an overview and some visual description of some of these phases also. The interview data was transcribed by hand in accordance with Phase 1 of the thematic analysis model used. Coding was done also by hand, using multiple lists, highlighting and reflective notes and then brought together to generate initial themes. Interview data was the primary source to begin the coding and theming process but was triangulated with notes made using the clinical reports available about the women. Notes had to be made while on site as clinical reports could not be accessed remotely. These annotations and comments along with my own observations using field notes and reflective accounts while in the clinical environment were consulted and considered in line with the coding and initial theming from the interview data. This data together formed the basis for analysis of a case study.

#### Phase 1

Analysis began at Phase 1 identifying common words and phrases from each interview, noticing similarities in answering style, similar words used for description of the environment, alluding to past experience just to give some examples. At this point I also spent time reflecting on what this might mean, given the additional data I had in relation to the individual women and my own observations while conducting the interviews. During these initial phases as outlined within Braun and Clarke's model I began acknowledging these words or sentences deemed to be either significant or interesting due to their repetitive nature, unusual nature based on previous writing and knowledge around this subject area or perceived as being significantly different based on gender and the care and treatment of women with a learning disability and associated mental health disorder. I deliberately chose not to use any additional software at this point or at any other point of the analysis stage as I wanted to feel close to the data, particularly as interviews were not exhaustive or long and it was important that I could spend time reading multiple times, listening repeatedly to the women talking and making my own notes. Having these visually in front of me helped to find meaning in what they were saying. Transcription itself also formed part of this first phase.

#### Phase 2

Phase 2 of the Braun and Clarke model is generating codes following any transcription, reading and re-reading within Phase 1 and in this case, multiple times listening to the audio recordings of interviews. This was done following the first set of interviews at Host Site 1 and then again with all interviews as one set following the second set of interviews at Host Site 2.

Braun and Clarke identify this stage as noting interesting features across the data set and gathering data to codes, possibly coding more than once to find that succinctness within the data. I went through the initial interview transcriptions and made notes of interesting words, phrases, concepts and once these started to become saturated I then began to "re-code" these into more manageable codes that reflected similar features. The list below shows my first set of thoughts that I wrote down from reading transcription, listening to audio and also noting features within written care reports and discussions with staff. This was also demonstrated using post-it notes, highlighting data extracts and having all of these in front of me during each part of the analysis stages.

Figure 2 Initial Coding - Phase 2



The table below shows the coding process which aligns to Smith's suggestion for coding approach (1998) but allowed me to consistently apply codes to the features identified in the transcriptions and recordings. This was completed through repeatedly listening to the audio recordings, reading my observation and reflective notes and also any notes made in interviews where the participant did not wish to be audio recorded.

**Table 6 Letter coding for Phase 2** 

	Letter coding (per initial transcription) – Smith (1998)			
Α	Difficulty recalling time / making sense of time			
В	Telling rumour – what I've heard – happened to someone else			
С	Shame			
D	Self-deprecating Self-d			
Е	"horrible"			
F	Acceptance – shrugging, staff decide			
G	Relaxed – throwaway comments - humour			
Н	Perception of fairness			

1	Alluding to past trauma often without detail
J	Sensory needs and noise sensitivity
Κ	Importance and perception of staff – have to talk to staff
L	Insight
М	Boredom – lack of activity
Ν	Unrippables (strong clothing) and self-harm - dignity
0	Multiple placements
Р	Medication
Q	Patience - waiting
R	family and identity

The transcriptions reflect this process as follows: Below shows some of the initial codes attributed to Celia and her first and second interview. Not all initial codes are included below.

# Celia - a) Difficulty recalling time

Couldn't tell me how long but intimated that she was sometimes in for a couple of hours and other times overnight and that she would say she was calm in order to get out.

# b) Telling rumour

Heard that sometimes staff won't give you a mattress saying 'you only want to go into seclusion so you can sleep'

ME: Have they ever said that to you?

"no, not to me"

d) Self-deprecating

e) "Horrible"

"It's horrible when they put you on the floor and put the unrippables on you"

"They strip you down...that's horrible"

I) Insight

"...won't let you out unless you have PRN"

- K) Importance and perception of staff
- i) Alluding to past trauma
- n) Dignity

Celia reports that you can't go to the toilet unless you are settled. And that she had heard some women had wet themselves. This also relates to code b).

This process was then applied to all of the interviews from Host Site 1. The overlap of repeated words, phrases and ideas were noted to create the alphabetical coding initially, in order to be able to notice common features in the interview data.

Coding was initially given its own letter of the alphabet, taking at first the concept put forward by Smith in his IPA analysis model (1998). This allowed for collation of different words, phrases, commonalities in language. However, once this stage had been applied to my entire first set of data this produced a saturation, repetition and at times the need to cross reference due to the apparent similarity between some words and phrases used. The nature of the written data often presented in single word answers or words that were simplistic in nature and meaning meant that a fuller approach using concepts of discourse analysis were not always applicable (Potter 1997) and meant that Thematic Analysis felt appropriate and would also allow for further exploration of meaning behind the data by the wrapping around the analysis process of the individual feminist approach to the study. As has already been mentioned within Chapter 3 and the interviewing process adopted, the environment and occasional governance related limitations at times meant that I felt a complete reciprocal relationship to the data gathering stage was not entirely achieved and this will be discussed further within the discussion part of this thesis. However, what was supportive of continuing to maintain a good perspective on the aims and values embedded within the research study was the ontological, epistemological underpinning, ensuring that I was able to refer back to my own knowledge, the knowledge of others supporting the research process and my own reflective writing throughout the data collection phase.

The first set of generated codes were able to then guide a further, more robust set of coding. This time colouring was used not only to highlight key words, phrases, but also similarities in how the participants answered questions and their presentation on the day of interview. I completed this by manually annotating and highlighting sections of each interview transcription so that the features as identified in the initial coding phase shown above could be drawn more easily together into a clearer, more concise set of codes. At this point, these do not constitute themes as they are a continuation of re-reading and revisiting the data and continuing to make note of features, similarities and centred more around the language and references made by the women. This was then cross referenced with the second site data and also interview / conversational data with clinical staff and then with information regarding the women relating to their clinical diagnoses, history and

forensic presentation. I was also able to begin to bring in my own reflection and the observations (Yin, 1993) I had made following each visit and interview.

Table 7 Phase 2 – 3 Coding continued

Colour coding			
(per each transcription following initial letter coding)			
Yellow	referring to "them". This is staff, staff actions, decisions by others and behaviour of staff		
Blue	various short descriptive words without further detail but that become thematic and consistent across different interviews, units and sites. Include words such as "horrible", "blue", "cold" – these words denote feelings and emotions		
Red	Denotes trauma – references to difficult pasts that make the seclusion experience more difficult		
Green	Words used to physically describe the experience – e.g. references to windows, doors, showers, mattresses which again then go on to provide evidence of the experience		
Purple	the throwaway – linking in to various other topics, e.g. referring to self-harm, assaults on staff, being held, "kicking off"		
Orange	Insight – into own needs, reasons for seclusion, perception of improvement, support requirements e.g. PRN and DBT skills		

# Phase 3

Following this Phase 3 of the Braun and Clarke (2021) model was employed to explore how these codes could be generated into themes. Supervision and discussion helped settle on the number of themes. Reflection ongoing throughout the process and relating back to Nowell et al. (2017) model and Braun and Clarke's own reflexive guidance (2022) meant that drawing thematic maps, writing lists and keeping detailed notes of discussions with both supervisors and my own reflective thoughts supported in determining wider themes that then fed directly into Phase 4 and 5 of analysis where constant review of the themes occurs. Below is an extract from one such reflection which outlines that initially themes based on the initial coding numbered around six. The coding was referred back to consistently throughout this stage to ensure that what I had initially deemed to be important was fairly represented within the themes being generated.

THEMING THOUGHTS – colours reflect importance attached to particular words or phrases

- 1. LANGUAGE AS REFLECTIVE / CONSTRUCTED / SYMPTOMATIC of / from the hospital environment WHAT DO I MEAN BY reflective? Reflective OF THE ENVIRONMENT, DIAGNOSES, HISTORY, THE SYSTEM based on their talking of their use of PRN, description of the colour and feel of the seclusion room and the process of using different skills to manage aggression and violence, e.g. DBT
- 2. SPACE TO CALM SENSORY NEEDS, THE ENVIRONMENT codes mention time away from the ward
- 3. SUPPORT TO CALM ROLE OF STAFF, ROLE OF PEER SUPPORT

Following supervision this will be one theme based on using seclusion for different reasons and the role the process of seclusion plays in calming.

- 4. EXPECTATION SELF-WORTH, THIS IS WHO I AM TRAUMA, SELF-WORTH & SHAME can I include some of the idea of dignity and processes / procedures within the seclusion room (personal hygiene, being watched also identified through the social and personal histories of the women and their background of mental illness and abuse.
- 5. They the staff role importance, hierarchy, support, power codes around using skills to calm, speaking about staff and support or even the description of male vs female staff or not understanding the process or the situation.

Themes, while they were emerging based on the initial codes also began to overlap. For example, the idea of sensory need and space away from the ward to calm was a little mixed with the role that staff play in supporting the women to calm as well as the lack of acknowledgement that seclusion is used as a last resort by staff where required. This meant that defining themes was very much determined not only by the codes but also by triangulation and peer debriefing (Nowell et al. 2012). This allowed me to provide more credibility to the choice of themes based on a more deductive process that prevented me simply from gathering up the codes and forcing them to fit into a predefined theme or even to risk ignoring previous acquired knowledge that meant that data that was not necessarily there in abundance throughout all data sets and interviews but may be significant in providing further insight into the topic and helping to answer this particular research question.

#### Phase 4

Below is an excerpt from my own reflective notes following a meeting with the research manager from Host Site 2 once data had been collected and codes had begun to be analysed.

Women – identity e.g. Julie appears to have knowledge of herself and her consistent way of expressing. Natalie – unsure of who she is when discussing – how long would it take to know these

women and understand their behaviours? How important is trauma informed care specifically within this group?

The women sometimes need seclusion, time away, time to be on their own. The idea of shame and dignity if remaining on the ward under the influence of PRN appears to be more overwhelming than being away and in the seclusion room. Over stimuli perhaps.

Similarly, a follow up discussion with Dr Fell (see triangulation sub section further on in this chapter), the current Responsible Clinician for the wards visited at Host Site 1 deconstructed and relieved me of the idea of shame and dignity among women in particular being a key theme following analysis of the data. It was something that one woman had said along with one other member of staff early on during the interview process that had allowed me to consider the idea of shame as key to the female experience of seclusion. However, my reflective thoughts following further exploration are shown below:

Shame – some reading on the issue of shame. Two comments from staff and from one interviewee. Had not found much at all in the literature and then host site 2 did not confirm this particular code. RC felt that this was perhaps an individual issue, perhaps based on individual traits or difficulties based on history rather than gender. RC felt that the issue of shame linked in with interpersonal relationships and this may be just as difficult for men and would very much depend on that person and their relationship with both staff, peers and the ward environment. Issues of culture have been often touched upon in the relatively smaller discussion on female services and this also appears to reflect the issue of disparate diagnosis also (EUPD). Given the desire to use reflection and not to simply accept based on my knowledge of female services and a key aim of this study to re-examine previous held assumptions in relation to restrictive practice and gender I do not feel at this point that shame as a code / theme warrants further exploration although does warrant comment due to what this may represent.

However, further discussion with the RC also supported another theme that had begun to emerge following my analysis of the generated codes:

...they related that they would use seclusion as a way of retreating from the ward environment, sabotaging their planned care, e.g. discharge planning and also to reflect their own sense of selfworth – once a member of staff had made the decision to use seclusion (the last resort) then this simply served to convince the individual that what they believed about themselves was in fact true.

Additionally, looking back at my notes when recruiting potential participants at Host Site 1 I was struck with comments I had made regarding one woman in particular which served to further highlight issues which would go on to define the themes I then chose and support the comments above made by Dr Fell.

...Would this person be able to engage? In order to at least try to consider this would I need to extend my proposed interview schedule in the hope that her health and well being would improve

and the interview could take place? The information I was provided with also intimated that this person often sought seclusion as a way to ensure safety. This was interesting, thinking about the recent and current drives to reduce the need for seclusion. What were the alternatives for this?

The section above has highlighted the complexity and reflexive nature of next phase of the Thematic Analysis model employed (Braun and Clarke, 2021). It demonstrates how coding had been used throughout the interview data sets and as part of the Case Study methodology utilised in order to bring in fuller, supporting data to the cases themselves. At this point themes began to emerge that centred around the women's use of language, the common interpretations of the environment and the link back to their earlier experiences, often associated with high levels of trauma and dependence and had been clearly identified already in Phase 3. However, certain ideas and concepts such as that of shame as being common to the entire dataset began to emerge as unique only to certain individuals so while important certainly did not warrant the naming of an individual theme. It was also important that I was able to relate the themes at this point back to my research question and objectives. The study aims to capture the experiences of the women but in particular relation to the use of seclusion and also to inform future policy and practice where applicable. It was important that themes and discussion generated was rigorous and well supported through the thematic analysis approach.

## Phases 5 and 6

Themes were then defined within Phase 5 of the Braun and Clarke model which were:

- 4. Cultural construction and language
- 5. This is me Self-perception and what defines the female and learning disability experience
- 6. Hierarchy, support and power the importance of staff

Each theme is explored in detail, showing its origins and analysis that incorporate Phase 6 of the analysis model within the next Chapter, entitled "Findings". Earlier phases of the analysis process including codes and the way in which themes were ultimately defined are referred back to. In addition to this, the three themes defined within Phase 5 are devolved into sub-headings to demonstrate the dataset and analysis process informing the choice of the that theme.

## 3.7 Chapter Summary

This chapter has set out the aims and objectives of the research summary and then considered them within a suitable qualitative methodological framework, namely Case Study research (Stake, 1995; Cresswell, 2007). The feminist paradigm first introduced and discussed in the introductory chapter was revisited and then utilised throughout the chapter to define how Case Study research would be applied to this study through consideration of reflective discussions, focus on interviewing style that had the female experience and researcher / participant relationship in mind. Using Case Study methodology was outlined more specifically, detailing the kinds of data that would be used to form a complete data set and then this was used to identify a good way to analyse the data, once again ensuring that the role of reflexivity, rejection of hierarchical research approaches was considered. Thematic Analysis as identified and set out by Braun and Clarke (2021) was used and the initial coding leading to reflexive consideration and the formation of themes was also presented. We also met the women whose voices were the thing we wanted to capture in order to begin to answer this research question and meet the aims and objectives of the study.

# **Chapter 4: Findings**

## **4.1 Introduction to the research findings**

The results do not simply show what I found and the way in which I found them but are able to demonstrate analysis leading to interpretation which will be explored further in the Discussion chapter. What this chapter will do is show how I stayed faithful to the way in which I positioned myself earlier in the thesis, in that I would present these findings by honestly and faithfully representing the voice of the women I interviewed and supported with additional data in order to add further value to their words and their reflections. Also, I go back to the qualitative Case Study research approach of Stake (1995). Stake refers to the intuitive processing that happens when the researcher looks for meaning in the data they have gathered (2005: 72) and also goes on to remind us that case studies by the very nature of the relationships involved are complex. This is once again where reflection in the robust nature of the analysis is important but also lends itself to empower the researcher into discovering something quite new and exciting in their research. This study aims to find new knowledge in within the experiences of women with a learning disability and add to the seclusion debate and discussion going forward. The findings will show that their voices certainly lend a different perspective to this discourse.

## 4.1.1 Revisiting the Thematic Analysis findings and themes

The results and the analysis journey will be shown to further demonstrate Phase 5 and 6 using the three themes identified in Chapter 3 as sub chapters. Phase 6 is aimed at weaving together the narrative through analysis and contextualising using existing literature. It is precisely this choice of reflexive thematic analysis model which provides justification for using this literature in conjunction with the finding presented in this chapter. This allows for the clearer development of the themes and to show as per Phase 5 also how they have been confirmed and finalised. Using existing literature as advocated by Braun and Clarke (2022) also allows for new knowledge being generated to be reflected within the feminist framework that I have chosen for this study. This is evident through examining findings in a different way and its connection with previous studies. In addition, using existing literature within this chapter, as well as adhering to the thematic analysis framework (2021) being adopted, allows for alignment to the earlier literature review and to begin to expand discussion as we move towards the discussion and conclusion of the thesis.

Each theme will be explored using the transcripts and interview data from Host Sites 1 and 2. Transcription examples used will also demonstrate the coding process as presented in the previous chapter and how these were interpreted to represent the theme. Not all transcription examples will be provided for each theme and its sub-headings but those which provide a rich example of the point being presented and a good example of the analysis process.

To remind the reader the three key themes identified through the thematic analysis are:

- 1. Cultural construction and language
- 2. This is me Self-perception and what defines the female and learning disability experience
- 3. Hierarchy, support and power the importance of staff

### 4.1.2 Using reflexive writing to develop themes

Reflective writing, as shown in Chapter 3 supported in developing the overarching themes following thematic analysis. Nowell et al. (2017) describe reflexivity within the analysis process as central to the audit trail and being able to demonstrate how particular themes were constructed and developed. Reflective discussions with clinical staff, my supervisors and consistently jotting down notes to check against my values and initial positionality meant that I began to consider what was key to the women's experiences that could be demonstrated through their interview transcriptions as well as the nuances that were not present in the wording. It was important therefore that I did not use these transcriptions purely at face value and that reflexivity was able to guide me in ensuring there was a robustness and a validity to the themes that I had interpreted. Reflecting upon language for example was what led to the decision to name Theme 1. I began to reflect with supervisors on how language was expressed through the interviews and then in comparison with clinical report writing on the women. A reflective conversation with a social worker for example allowed me to consider the feelings of anger linked to past trauma, abuse and also the masking of ability in relation to one of the women I had spoken to. I had become a little confused around the reasons she gave me for her being put into seclusion and my feelings had become a little angry towards the service around the treatment she reported to me. Allowing myself time to consider this in relation to the hospital protocols and the assessments conducted around her behaviour and support were then considered in thinking about language differently. I was able to consider the cultural hospital influences on the way that the experience of seclusion was presented to me by the women.

Once again, the second theme needed careful consideration. Coding and initial theming relating to self-harm, trauma, dignity, and lack of power meant that these were not areas of the seclusion experience that I could ignore. However, I did not wish to present these in the way that women had previously been presented in literature, either using words and phrases relating to management difficulties, prevalence, and intensity. I wanted to reflect what was unique about these women and the ways in which they challenged the systems, their care and strove to communicate their emotions and their needs. I wished to demonstrate their uniqueness also in that not all of the women had the same perception or experience of seclusion or indeed the same way of expressing what that was. One example of this might be when I asked Tattoo how she felt when undressed in the seclusion room for her own safety and she replied that she wanted to "slap 'em in the face...even women". I took time to reflect on what such a shocking statement might represent for her rather than to begin to consider this from a more traditional behavioural point of view. Therefore, this comment for me was framed within the past sexual abuse and trauma that she had experienced when a child, something I had learned in reading about her history through clinical reports and speaking with staff.

A number of seclusion texts and studies have either referred to or explicitly compared the staff experience of implementing seclusion with that of the service user. I explored within the interviews with the women the role that staff played for them when in seclusion or going into seclusion and also the women answered a number of other questions in a way that implied the importance of staff. Again this theme title was developed on an amalgamation of coding which incorporated more negative views of staff, concerns around the gender of staff secluding the women and just as importantly, the support that staff either did give or the women feel they should give to them. The feminist paradigm to this study represents a focus on gender, rejection of hierarchy and considering the experience of seclusion through a less patriarchal and traditional lens in order to develop new knowledge on this subject area. Staff deserve their place in the overall themes.

While listening back to initial recordings it struck me how difficult it is to not ask closed questions due to difficulty in expression and very short, often confirming, one word answers. More open questions can tend in some questions not to elicit much information. I felt the need to guide although on reflection I am wondering about methods and the best ways to get this information. Could a focus group spur more spontaneous thoughts and conversation? Perhaps not dependent on the dynamics of the group...

Although not a very long or detailed example given here, what these thoughts did allow me to do was to continue with further reading around qualitative interviewing and those with communication difficulties. Previously I had, perhaps quite arrogantly (Morley, 1996) considered my own

background and experiences as a learning disability nurse to be sufficient in order to carry out this research. I believe(d) in the person-centred approach, in being holistic and facilitating good communication. However, further reading allowed me to really consider my own communication almost to the letter. Conversely, rather than make me realise that I needed to do things differently or "better", this reflection and subsequent actions actually reinforced that much of my data was richer than I perhaps gave it credit for (Hollomotz, 2018) and that I did need to acknowledge some of the perhaps more positivist approaches through the use of protocols and processes of the host organisation which limited my ability to conduct the interviews in any other way on that particular occasion. This once again reinforced my epistemological position and the importance I had placed on my own experiences and intuitions as part of the research and interviewing process.

### 4.2 Cultural Construction and Language

Sub-headings used in this section entitled "Cultural construction and language" will draw on initial coding from thematic analysis so that the use of language within the interviews will be explored including codes relating to mirroring of institutional language belying meaning and understanding and also reflecting the power balance experienced by the women. Language used consistently to describe seclusion and the experience will also be used in order to build a picture of the female experience of seclusion more generally. All transcription and interview data will be triangulated with relevant information from observations, reflective accounts, staff briefing and Case Study reports on the women from Host Site 1.

Larkin et al. (2009) refer to secure systems within constrained environments as being open to promote manipulation and reconstruction on the part of the staff or hospital systems themselves. Larkin attributes this partly to legislation and its use and interpretation within such services. Essentially what this means is that people are then far less able to exercise true choice and expression relating to their care and treatment because of the legal frameworks that govern their experience in hospital. This discussion by Larkin is one pertinent to other themes and additional discussion but has been used to open this theme as also reflecting the way in which systems manipulate and influence individuals who are at times lacking choice and power within society. The discourse around women and nursing them within secure hospital environments has been longstanding (Williams et al., 2001; Aiyegbusi, 2002) and their reputation certainly precedes them. It was not uncommon within my own previous practice for staff to become resistant or even fearful when told they would be required to work with the women. When discussing concepts of

treatment, assessment or just ways of managing unwanted behaviour within a ward environment, 'valued behaviours are commended; non-valued behaviours, if not exactly punished, must be seen by the service user to be associated with undesired outcomes' (Yates, 2005:233). Yates here is referring once again to the concept of power and coercion exercised by services or institutions themselves, however this particular quote is useful here to highlight that this appears to be how the women also interpret the reasons why they are placed into seclusion based on the data from this study. Lloyd et al. (2006) also refer to this concept of disempowerment and people with expressive language difficulties and that traditionally in research they are overlooked and that it is important to find meaning in what they exclusively have to say.

Choosing the term cultural construction was a considered choice with culture reflecting the institution which includes the ward, wider hospital, and the service within which these are provided and governed. Cultural construction also reflects the social and political discourse surrounding the female experience, that of someone with a learning disability and staff professional codes of conduct. The word cultural was selected over something more constricted such as institutional or professional because the way in which these women experience seclusion, other restrictive practices and treatment is being considered in this study with the hope that findings can be influential not only within the hospital or setting itself but within wider discussion.

## 4.2.1 Learning Disability and the implied through simplicity

The women themselves did not always use what we would consider articulate, complex language. At first sight it would appear that interview data lacked both content and richness at times and this was generally across the full range of interviews that were conducted in this study. The women often said things in a brief and non-expressive way, using words such as "horrible" frequently to describe the room and the experience itself. When pressed on further detail they often appeared to struggle to provide any more information or insight. At times staff needed to intervene within the interview process to support communication and subsequent meaning, although to what cost will be discussed in the next chapter. This is in line with my own experiences of working with people who have a learning disability or who may sometimes struggle to communicate everything articulately and verbally (Emerson, 2011). The language was both familiar to me as someone with experience of working within similar clinical environments but also at times confusing given the varying terms for aspects of seclusion and local colloquial language. It was therefore important that I was able to interpret or see the importance of what the women were saying while minimising the amount of influence projected on to the individual responses themselves. Goodley (1998) mentions that this

risks compromising the richness of the data along with cultural and research bias potentially tainting the data also (King, 1997; Lloyd et al., 2006). This is illustrated in the below interview passages.

Me: So why have you got to spend a week in there?

Bethan: Cos I's bes bad.

Me: Right. So tell me what bad means.

Bethan: Like..kick off.

Me: Oh ok right. And how's it make you safe if you go in the seclusion room? Do you know

how?

Kate: They make me have a nightie on.

Me: Right ok

Kate: Not everybody does.

Me: Is it a special nightie?

Kate: Yeah.

This example shows that the idea of safety and reasons why seclusion may support with this was not easily processed and therefore explained by Kate but she was recalling details, sometimes apparently not directly prompted by my specific questions. However, my question may have prompted thoughts of being kept safe from self-harm and therefore the need to be placed in strong clothing or the "nightie" as Kate refers to it.

# 4.2.2 The "Cloak of Competence" – masking and understanding through language

Edgerton in his seminal work "The Cloak of Competence: Stigma in the Lives of the Mentally Retarded" (1967) explores the lives of a group of people with learning disabilities, traditionally segregated from society in the US. The similarities are not lost in considering those with a learning disability who are currently deemed too risky to be supported in wider general society. Edgerton describes how the patients cover themselves with a "protective cloak of competence" (cited in Driscoll and Walmsley, 2018: p. 22). While Edgerton is referring to wider marks in society including relationships and employment the concept felt as though it could also be applied to the data that I had generated through my interpretation of the way in which the women often responded to questions and the language they used in these responses.

Interestingly in one case (Bethan), further discussion with her on-site social worker revealed that she often "masks" her lack of understanding through using more highly cultivated language and therefore projecting that she in fact understands more than she really does. This had also been something I had seen written about other women in similar hospital settings during my own time working as a nurse.

Me: ...do you go straight into the seclusion room? Or do you get held on the floor for a bit first...or what?

Bethan: Held on the floor for a bit first... and then put straight in seclusion

Me: And why do you then go into seclusion?

Bethan: cos it gets worser.

Me: Cos you don't calm down?

Bethan: [REPEATING]...don't calm down yeah.

Although conversations with staff and clinical reports would suggest that this way of interviewing Bethan did not perhaps yield true information it is difficult to know whether that is really the case. She may have been simply repeating my own words or perhaps my words were sufficient and she just knew what she meant and couldn't explain this in further detail. Clinical reports for Bethan relate incidents of prolonged attacks on staff, kicking, biting and using her strength to resist both being restrained on the floor and being put into the seclusion room. This information provides a little more context and depth to her words. She doesn't seem to be able to tell me, or won't tell me what not calming down means but the written reports provide a little more detail about this.

There were multiple interviews within both Site 1 and Site 2 that echoed this kind of language, coded to reflect the environment and clinical ward area. Interviewees were asked the reason that the seclusion room was used or what they did when in the seclusion room. Answers varied little to reveal stories linked to self-harm, assaults on staff or others but detail was usually scarce. Sentences, while sometimes short and apparently innocuous were also reflective of assuming that the listener (myself) knew the way in which care was given within the hospital. Some examples of are written below.

If I, er hit staff or if I get poorly sometimes, I do that sometimes (shows me cuts on her arms and legs)

I haven't done it for ages but when I do that sometimes they put me in for my own safety. (Kate)

Bee: When I attack people

Me: When you attack people...ok. So when you attack people...?

Bee: ...and pull their hair

Me: And pull their hair...

Bee: ...and glasses

Me: And do you go in the seclusion room straight away? Or do you go in after a little while?

Bee: If I do it constantly then yeah

Debbie: Cos I was threatening the staff

Me: You were threatening. Did it take a whole week to calm down?

Debbie: No

Me: No, how long did it take for you to calm down when you went into seclusion?

Debbie: About two or three days

Me: Right...but you were in there longer than that? Ok. Why do you think it took so long to come out?

Debbie: Cos I did something serious

However, some women would use this kind of language with little detail but then describe circumstances such as feeling "overloaded", "coping strategies" and "poorly" and "settled". While seemingly innocuous or throwaway words, the women could not then always describe what it meant to be "settled" or "overloaded". They would refer to ideas such as "using DBT skills" but then put greater emphasis on requiring staff support to do this.

One interview where the women being interviewed was often providing very short, simple answers with poor grammar at one point used this phrase:

Me: Ok, do you have PRN?

Bee: Only if I require it

I found this one response interesting as it was suddenly as if someone different had answered the question, however, she was then unable to tell me what she meant by "require", repeating the word and not able to answer when I asked whether she knew when she "required" medication.

Me: What about it helps you to calm down?

Bee: Less stimulation

Me: So less things around you that could...?

Bee: Overload

This use of more complex language appeared out of character for Bee and this was confirmed by the member of staff who was with her during the interview. I did not have access to any clinical notes or records for Bee as she was at Host Site 2 but this feature of a number of the women using language that was consistently reflective of the service or even the institution was notable.

When discussing processes the women will often refer to clinical terms and use phrases more commonly used by clinical staff and also reflective within clinical reports. This has led me to question the knowledge of the women around certain aspects of their care, such as the use of PRN, clinical holding, reasons for being secluded initially and compliance.

Excerpt from a Social Circumstances report relating to Jay (Host Site 1) — "...During her stay at the \*\*\*\*, initially she appeared to be using the service appropriately"

Words such as "settled", "appropriate" "working with staff" and "positive engagement" are littered throughout the reports on each of the women from Host Site 1. Interestingly this kind of language is also evident through my interactions with the women. The language belies the level of understanding of the women as experienced by myself during the interview process when I was able to ask Jay what she understood by being settled. During the interview she was telling me about when she was able to leave the seclusion room and the reasons why she goes into the seclusion room. The word settled was referred to more than once and when I asked her to try and explain what this meant, she would just say "just like settled". This unspoken meaning behind various phrases and words, demonstrated in reports that are not able to be interpreted beyond their general meaning but that are readily adopted by the women themselves also causes some issue for the researcher making sense of this data. This is where I felt my positionality, bringing in my knowledge of female services and experiences of working within similar environments supported my

analysis to find meaning in this particular feature of the interviews. The Case Study approach was

able to support this meaning due to clinical reports providing an overview of the women's clinical

presentation and details of incidents of violence and aggression.

The women would sometimes for example refer to PRN using that term. They knew that meant

medication as I would sometimes ask to clarify what they had. They would describe injections or

using both haloperidol and lorazepam to calm down but often associated these with a clinical

requirement for release from the seclusion room. This directly contradicted the view of the RC at

one hospital regarding the correlation and relationship between medication and seclusion. The RC

described the relationship between the use of PRN and seclusion as independent of each other and

that most women would use PRN during early stages of feeing agitated and upset in order to calm.

4.2.3 Hours, days and weeks – the significance of time

There are times when it would appear the women trivialise what would seem to be quite significant

issues or extreme language. One example is time, do the women understand time or does it not

seem that hours spent in the seclusion room is deemed a long time because of how they generally

experience hospital life? While at first glance this sub-theme may appear to describe actual

experience rather than focusing on language and how they refer to their experiences, it has been

included here due to its abstract nature reflected in the women's responses. Temporal experiences

and perceptions as detailed through description also begins to demonstrate emotional responses to

the seclusion experience and at times even a sense of injustice, powerlessness or even apathy to the

length of time that someone may be required to stay in the room.

I've only been in seclusion for about like ten hours. (C & S)

"Stuck in there for a week" (Georgia)

Me: No. So how long are you usually in restraint for before you go into the seclusion room?

Tattoo: I'm not really sure.

Me: Do you think its quite a long time?

Tattoo: [speaking uncertainly] about 5...10 minutes.

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The transcription examples above seemed significant to code as once again it highlighted this idea of time being fluid and not necessarily understood well by the women, or even expressing that they weren't that interested in time. Maybe it didn't mean a lot to them. Language around time was once again throwaway and said in a matter-of-fact manner, by all women, whether describing being in seclusion for a week or a matter of hours. The quote above seemed significant as the idea of someone being held in restraint for a few minutes before seclusion was initiated was interesting and a bit perplexing. This is generally due to the concept set out in the Code of Practice (2015) and also our approaches to managing behaviours of concern with approaches such as Positive Behaviour Support and de-escalation techniques. To seclude someone is often when the need to use restraint for longer periods of time is high. However, this is not completely different from some of the literature relating to incidences of restraint, seclusion and gender where women are more likely to be secluded more quickly than men even if not more frequently. (Happell, 2011).

Within the interview below, where the participant was quite eager to talk about her experiences and fairly animated throughout the interview, the code of time once again emerged, and was described in a very nonchalant manner, but also there was language and acronyms used which implied that we all know this system and how it works.

Me: How long are you in there for?

Tattoo: They've kept me in there for about...once it was four hours and something I think.

Me: Ok. Not longer than that? You haven't been in longer?

RC: When you were in \*\*\* you were in long term seclusion

Tattoo: Yeah, when I was in \*\*\* I was in LTS

The use of the term "LTS" rather than simply repeating what the RC had said gives some insight into the knowledge of how the processes work within hospital settings. A2 refers to where she was secluded, staff apparently using her bedroom when the seclusion room was being used by someone else, and alternates between "LTS" being 3-4 months and 3-4 days which seems unlikely that this would be considered "long-term" from a procedural point of view, however, given that Tattoo reported that her time within her current hospital spent in seclusion was a few hours, this may have been important to her. Words such as "stable", "disruptive" and "containment" were also prevalent throughout clinical reports.

A quote from Georgia stating she was sometimes in seclusion for around a week prompted me to ask if she did anything when in seclusion for during that time and Georgis said she didn't really do anything. She did say that she slept, but only when asked directly. Once again, she refers to being "poorly". On this occasion though it would appear that the language, implying some clinical insight also serves to gloss over the reality of what is happening. When asked what "poorly" meant, Georgia began to try and shut down the interview saying "I don't want to" (tell you) and "I've had enough".

Other women in their interviews also mention sleeping frequently and sometimes describing using sleep as a way to pass the time and also due to lack of other stimulation.

Me: Right, is there anything to do when you're in the seclusion room?

Kate: No, I just go to sleep. And when they come in...talk to you...just wake up.

Me: So what do you do when you're in there?

Natalie: Nothing to do really, I just sleep and its really boring. Can't watch tele either.

This is also where a Case Study approach proved useful in that I was also able to verify that during the seclusion process it was well documented on the physical state of the women. This included vital signs monitoring such as blood pressure, temperature and respiratory rate as well as monitoring fluid intake, output and any other observations made during the seclusion period. I was able to establish this through seclusion notes at Host Site 1 and verbally at Host Site 2. However, this is not reflected in the social circumstances or mental health tribunal reports seen at Host Site 1 or spoken about by the women themselves. Some women did mention not eating much while in the seclusion room and the emphasis upon sleeping might indicate a potential issue with drinking, eating and personal hygiene. A search of seclusion policy does however stipulate medical review requirements but the details of this review are sparing and links to the role of the Responsible Clinician and the nursing staff.

# 4.2.4 Language and inside the seclusion room

One of the questions I asked the women throughout the interviews was to try and tell me in their own words what the seclusion room was like. What did it look like? What was in there? What

wasn't there? What could you do in there? At Host Site 1 and 2 I was able to see the seclusion room and form an impression of it myself. At Host Site 2 I gained an insight into the seclusion room from both the research manager and also previous research that had been conducted at one of the units.

This is taken from the PhD thesis of Rebecca Fish and her reflections of entering the seclusion room for the first time during her research.

The seclusion suite in the LSU has a door leading from each flat, a toilet room, and a door leading into the seclusion room. There is a 2ft by 1ft window in the door and conical mirrors at the back of the room in the corners which work to show the observer areas not visible from this window. A staff member is required to observe at all times. The only furniture is a bed, which is moulded in with the floor and holds a wipe-clean mattress. Lights and sprinkler on the ceiling are covered with rounded plastic. (Fish, 2018)

I asked Celia to describe the size of the seclusion room to me at Host Site 1, Ward 1. I cannot be sure that she was only describing the room on that ward given previous multiple placements, but her description was as follows:

Celia: "...could fit about 7 or 8 single mattresses in there". Heard that sometimes staff won't give you a mattress saying 'you only want to go into seclusion so you can sleep'

Me: What's in the seclusion room?

Celia: "Just walls...and a window...I'm too short to see out of it...I have to jump to try and see out of it cos I'm short"

This is quite specific. The use of mattresses to use as a unit of measurement is also reflective of a number of conversations relating to how the women spend a lot of their time while in the seclusion room. Tee also refers to the seclusion room and its dimensions as well as the tendency to sleep

Tee: I don't know how big it is. Not big...you can walk around if you...(trails off and becomes distracted by a staff member)

Me: Yeah, yeah. Can you see outside?

Tee: No, no. Don't like it cos I can't see. There's just like a window...and you can't see any...you see the daylight when its daylight but when its dark you just have lights on.

Me: Right, is there anything to do when you're in the seclusion room?

When coding the following words and descriptions were present throughout a number of interviews and across the two sites and different ward areas.

#### The "blue room"

A study conducted by Fish (2018) refers to the seclusion room as the "blue room". These are the words of her participants who are women with learning disabilities within a low secure hospital ward. The interviews I conducted highlighted particular common words and descriptions that give us an insight into how they feel and how they view the seclusion room. Their words often referred to colour, feeling, links to their own dignity and viewed through a feminist lens were particularly interesting in shaping a view of seclusion that may be unique to these women. By this I mean that when coding in Phase 2 and 3 of the analysis processes I was also considerate of why certain descriptions may be used or particular words repeated by the women, potentially relating to past trauma, being held, and the need for privacy.

To illustrate the language of seclusion from the viewpoint of these women I have chosen to focus on the codes relating to individual, repetitive words and phrases of description that were used across the entire interview data set.

These codes were coded as "blue" when colour coded. They were initially given letters for individual words or phrases such as "blue", "horrible" etc. However, the blue code denoted various short descriptive words without further detail but that become thematic and consistent across different interviews, units and sites. Other words included those such as "horrible" or "cold".

Regardless of which ward or site we were at the word "blue" was one of the most prevalent responses to the question asking the participant to tell me about the seclusion room. Responses varied from "big blue room" to simply mentioning it as the "blue room" rather than say seclusion room within sentences, almost as a throwaway comment and without realising this is how they were referring to it or knowing that I may not realise this. Some women also refer to the "blue bed" that is in the seclusion room, matching with the colours of the walls and often the only other physical item in the room when the women enter.

The interview transcript with B below (Host site 2) was interesting because she began to describe the seclusion room as lonely and cold but then went on to talk about the colour. Although she didn't

relate this to being cold it did make me think about a possible correlation as women at both sites had often referred to the room as being cold.

Me: Right, so, I'm trying to find out about what its like when you're in seclusion.

B: Lonely and cold

Me: So its lonely? Ok, so do you want to tell me a little bit about the seclusion room?

B: Its boring.

Me: Its boring. Why's it boring?

B: Cos its blue.

Me: Ok, would you prefer it was another colour?

B: Purple

Me: Ok, and why is blue not a good colour?

B: Cos its dull

I am not suggesting that the word blue or the colour blue bely any deeper meaning although it is certain that the women associate the experience of seclusion with this colour. Bella's description is interesting as seclusion is frequently referred to as "dull" or "boring" by the women and the colour appears to symbolise this also for some of them. I asked a staff member at Host Site 1 why blue was so prevalent across seclusion rooms and she thought it may be to do with the perception that blue may be calming but this is not my impression from speaking to the women. However, they do share a common language and understanding of seclusion and what the "blue room" signifies and refers to. This is not a phrase that I had heard used by staff although they do seem to be aware of it.

The word cold along with the word "horrible" was frequently used by the women in interviews when asked to describe the seclusion room. What was interesting about coding this in line with other words such as "blue", "lonely" is that it is not so much a surprise to hear negative words associated with the experience of seclusion but that further questioning about whether they asked for additional warmth in the form of heating being turned up or extra blankets, some women then reported that they did not think to ask for this. When I reported this to the clinical staff immediately following interview at Host Site A they were surprised as they were in fact able to adjust the heating remotely but had often not thought to ask the women if this might be needed. The RC I reported this finding to said she would pass this information on to the ward staff. This felt connected to the theme relating to staff power and hierarchy, demonstrating a linking between themes but borne out of the consideration of the women and their use of language. Finding such as this within language

that at first appears to signify little show that relaying those experiences can in fact lead to positive change and practice implications.

Me: What about...some of the girls have told me about being able to have these blankets...

Bethan: Yeah, they're crap.

Me: has that happened to you?

Bethan: Yeah, yeah but they're rubbish blankets.

Me: What's crap about them?

Bethan: They're not that warm if you know what I mean.

Me: You get cold?

Bethan: Yeah

Me: And why do you have to have those on?

Bethan: To cover you over when you're going to sleep

Kate: And erm...they don't give you blankets. Sometimes.

Me: And how does that feel?

Kate: I don't know, it feels not nice to not have a blanket. You get cold.

Me: You get cold, yeah. So, is it a cold room?

Kate: Yeah.

The opening paragraph of this theme around the Cultural Construction and Language referred to the institution and the role of power and discourse. The results shown highlight difficulties interviewing women with learning disabilities in secure settings, difficulties ascertaining levels of understanding and the reliance of knowledge around processes in order to begin to understand how the women experience incidents of seclusion. Within Chapter 5 the relationship between language and the institutional influence will be discussed in relation to the results shown here. The results have begun to show commonalities of language shared between the women across the two Host Sites as well as difficulties in expressing what they experience beyond both simplified and established language. The results have begun to show that some of the smaller words and phrases used to describe the

experience of seclusion show that it is not generally perceived as positive or therapeutic and the description of the room and time spent in there that the women offer reflects this.

#### 4.3 This is me – The past, the present and the future of women in secure care

This is me aims to reflect the sense of identity through behaviour and institutional and societal response to that behaviour through the finer lens of gender. Within the discussion chapter this will also consider the role of social discourse and power but the results have been analysed and presented here to show how the women represent themselves and their experiences through their descriptions of being put into seclusion.

In 2017 the film "The Greatest Showman" was released, once again reigniting the western world's interest in the musical film genre. What was evident is that people identified positively with the song entitled "This Is Me", inspiring people to demonstrate strength and value themselves in the face of adversity and a society that tended to reject them. What followed was that the song, like so many others before and since, was used by minority groups including people with learning disabilities and their advocates to show themselves as valued members of society. Multiple versions appeared on social media platforms using Makaton, dance and endearing their cause to millions. This is always a powerful vehicle for instigating change in attitudes and making a minority group more visible and celebrated within wider society. More recently we have the Mencap Mythbuster campaign (Mencap, 2022) and other attempts to influence societal change including Heidi Crowter and her campaign to change the abortion laws in the UK in 2021

## 4.3.1 Trauma and feeling safe

During coding and reflective writing, themes that were central to previous literature reviewed around women with a learning disability in secure / forensic environments began to emerge within the context of the interviews and additional data collected for this study. Initial codes and thoughts relating to shame, dignity, trauma, past abuses and self-harm became quite prominent. This began to define the female experience within secure services and disability related literature also. In addition to this, a more recent trend towards trauma-informed care and treatment pathways within both mental health and learning disability literature was explored within the literature review chapter. A feminist approach to the data that the gendered experience was to be explored within this study and the use of Case Study as a methodological approach meant that moving on from the

literature, discussions with clinical staff and information from supporting written reports pertaining to the participants' care and diagnosis would also be used to support the interview data.

When interviewing the women, epistemological positioning and my own professional background as a nurse and nurse academic was acknowledged as being part of the data collection and analysis process. My positionality and framework to also allow some reciprocal questioning and for the women to acknowledge me as part of the process also shaped the relationship and the way that they responded. One example of this was when Bethan asked me about my pregnancy and rather than refuse to discuss it with her, I answered her questions as honestly as I could. She then began to tell me before we began our interview on seclusion about her own child and how she missed her. Questions were aimed at gaining as much independent knowledge about the seclusion experiences of the women, but questions were also designed through knowing something of what seclusion might mean to these women. By that it is meant that exploring the women's background and feelings around being held and then locked in a seclusion room may be interlinked and questions would certainly reflect this to some extent. However, it is important to know that this was not the focus of questions. Knowing these women well was not something that was available to me and therefore sensitivity and perhaps even staying away from some topics in detail was something that was decided upon between myself and the supporting research and clinical staff as part of the ethics process and planning stages leading up to the interviews themselves.

Coding began to focus on particular words, phrases and reactions that some women had to particular questions or at certain points during the interview. When initially coding particular words or phrases against the individual interview data sets, codes relating to self-deprecation, protecting themselves through refusing to recall certain aspects of seclusion, self-harm and clear reference to past trauma and abuse (though often without detail) began to emerge. Further colour coding denoted traumatic experience alluded to would then often impact on the way the women appeared to experience seclusion.

Combining these words, features and also some of the interviews when women would actively ask me to stop the interview when a question perhaps got too close to discussing past experience or difficult feelings meant that the theme "this is me" was discovered. Within the discussion chapter I will also outline a little more meaning behind the choice of this theme but it is essentially to reflect the way in which these women's lives have been defined and continue to be defined within current literature and

Interestingly during the first set of interviews at Host Site 1, I remarked on the often superficial

nature of the answers during some of the interviews. I spent a number of hours and supervision

time reflecting on my skill as the interviewer even though I felt I had obeyed my instincts to stay safe

and keep the women safe and comfortable during the time I spent with them. The Responsible

Clinician supporting me during these first interviews discussed this with me and felt that part of the

reason relating to stilted answers and superficial answers could be rooted in difficulty recalling past

events and trauma and was in fact a protective strategy for the women.

When meeting Georgia and Host Site 2 for the first time, she presented as withdrawn, although

friendly and respectful towards me. She was wearing oversized clothes and would be classed as

morbidly obese. Her self-care and personal hygiene appeared to be poor. When I was discussing

Georgia's interview with a member of staff they commented on the fact that Georgia herself had

reported and that it was documented that she did not wish to look or appear attractive so that men

would not approach her due to past sexual abuse. The interviews themselves did not reveal this

aspect of Georgia's life, nor should they have but it is important to comment on this as it is integral

to the women and their experiences.

Below are some of the transcription examples relating to this theme.

Kate: I said when you're in seclusion sometimes you get shoved in there...

Me: You get shoved...

Kate: And erm...they don't give you blankets. Sometimes.

Me: And how does that feel?

Kate: Horrible. I don't like being locked in cos when I was a kid I was locked in [ murmurs]

Me: In a where, sorry?

Kate: Wash house.

*Me: Oh, that doesn't sound very nice.* 

Kate: When I was a kid...so I don't like being locked in.

This conversation was then moved on naturally by Kate who did not want to talk about that further.

Cap: In seclusion, men restrain you and take your clothes off you

Me: Men restrain you as well?

Cap: Yeah

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Me: And how does that make you feel?

Cap: Horrible. Because of the past... I don't like it.

Me: Ok, so you've got memories that make you feel a bit horrible when that happens?

Cap: Yeah

The example above was unprompted and Cap was fairly keen and animated during the interview, happy to reveal that she found the experience difficult because of the past but not willing to be pressed on further details. As this was not the purpose of the interviews I refrained from further questioning relating to past trauma.

Further questioning within this joint interview with Sweet and Cap also continued to mention the fact that men are involved in the seclusion process and the effect this appears to have on these two women.

Me: Erm ok so...when you go in you've mentioned that your clothes are sometimes taken off.

Cap: Yeah, by men.

Me: By men. Ok

Sweet: And by women as well obviously

Cap: By women sometimes. But it depends...[incoherent]

Me: And by women as well.

Sweet: But there's more men. There's like one woman and ten men. In' it?

Cap: Yeah

Me: There's a lot of men?

C & S: Yeah

The involvement of men was a significant issue and strong theme within this particular interview.

In other interviews, past abuse and trauma was alluded to but as per the interview planning, women were not pressed for further detail, especially if they appeared to become distressed.

Me: You mentioned to me about going in seclusion because then you're not being restrained and you calm down. Do you find it hard when people are holding you?

Tattoo: Yeah I don't like it.

Me: Ok, what is it about that that's horrible for you.

Tattoo: Just something that happened. Yeah.

Me: Right

Tattoo:...in my life.

Me: So it makes you think about your past?

Tattoo: Yeah

Tattoo: I don't want to talk any more.

Me: That's fine, that's fine.

These are just a few examples but are exemplary of how interviews tended to flow. There are a couple of other examples of this. One such example of this was Natalie's interview within Host Site 2. Following this interview, we raised this through the local Safeguarding lead as there were disclosures within the interview which we had a professional responsibility to report and was also in line with ethical approval and consent. Without providing details of the disclosure here, it is sufficient to say that Natalie, similarly to Cap and Sweet within host site 1 also discussed how she feels being "stripped" by males and the feeling of being watched by male staff while in seclusion. While additional data from discussions with staff members, both Dr Sand, Dr Fell, and other nurses and social worker staff at Host Site 1 confirmed that it was not frequently males that took the lead in secluding women but it did happen. The perception of some of the women is a little different using their words.

Sweet's interview was quite candid as she articulates her trauma and fear while in the seclusion room. For clarification she had already mentioned her claustrophobia, that was not an assumption on my part. It is also mentioned within her clinical reports.

S: What would happen if somebody got stuck in seclusion and the staffs keys wouldn't work to open it?

Me: Ok, I hope that wouldn't happen (said with a slight laugh). I'm not sure. They would find a way of getting the door open. They would find a way. So, you've got claustrophobia have you S? Has that been a problem?

S: Well, I haven't been in seclusion for 9 months but the last time I was in there I was really scared. I was crying. I was so scared that I was sick in seclusion. That's how scared I was.

Emma at Host Site 2 comments on seclusion and the act of changing into the strong clothing that is sometimes referred to as the "unrippable" gowns. She describes feeling ashamed and paranoid when changing and comments on how it takes eleven people to hold her and get her safely into the seclusion room. Karen at Host Site 2 also comments on changing into the gown and saying that it makes her feel naked even when she is wearing it.

This sub-theme has shown that past experiences that include being controlled, abused (physically, sexually and psychologically) are factors that then contribute to the women's experience of seclusion. The act of being locked in somewhere, held and at times undressed can reinvoke these traumatic past experiences for some of the women. Some of the responses to my interview questions reveal a fear of what might happen rather than what does happen, so for example when Sweet expresses a fear of not being able to get the door unlocked or when put in rip-proof clothing, what could happen afterwards. This is another reason why the use of Case Study as a methodological approach has been so important here. Embedding past experiences and histories of the women into the current knowledge and its informing of my interview questions and style has meant that it has been easier to interpret these responses within the context of these women's real lives.

### 4.3.2 "Self-harm" and seclusion

Within the theme of This Is Me self-harm and its relation to trauma and coping was prevalent throughout the interviews. Self-harm as a prevalent feature within the female clinical presentation and its sometimes links to past trauma and abuse have been explored within the literature review chapter and explored more generally when considering the nature of care and treatment within female services and treatment pathways. It is acknowledged that women self-harm more prevalently, sometimes for different reasons and often in different ways to their male counterparts (Long, 2011). Within both host site 1 and 2 self-harm featured prominently within the interview process as well as additional supporting evidence and data that was triangulated in order to show the results of the study.

This part of the This Is Me theme will provide data evidence collected as part of supporting discussions with clinical staff and also through some of the written evidence pertaining to the women and their clinical diagnoses but before that is presented later in this chapter and also just before showing examples of the interview transcription data relating to self-harm, my own

observations will also be explored in relation to this. These are the notes I made initially upon meeting some of the women.

Meeting Georgia. Georgia presented with multiple marks on her face and hands. There were dents in her forehead and cheeks which were very noticeable. She told me prior to beginning the interview that she was not allowed in the seclusion room. She asked the staff supporting her to tell me why she couldn't go in and the staff member began to tell me about Georgia and seclusion by saying "as you can see...Georgia bangs her head quite a lot, that's her main form of self-harm..."

Meeting Natalie. Natalie presented with multiple marks on her face, arms and hands. In addition to this Natalie had little hair. On speaking with clinical staff they confirmed that this was due to self-harm rather than any medical condition. My initial reflective notes on the initial meeting with Emma also are below.

Meeting Emma. Emma presented as having many marks particularly on her face and hands. The more severe marks were around her eyes and cheeks, appearing to be burn marks or marks that had been made using an implement of some description.

Some of the transcription from Emma's interview will be discussed in this sub-section as her experience of seclusion is unique and she appears to have quite a different relationship with the seclusion room than some of the other women who have been interviewed.

Self-harm was discussed or mentioned many times throughout the course of interviews. There were examples where self-harm was merely referred to in passing, without the woman being interviewed becoming visibly upset and simply seeming to "gloss" over the subject as something that is simply normal everyday life within the context of the ward environment and seclusion. The transcription below also shows how the words of the women contributed to the coding outlined above and also shows the comments I initially made, consider certain words or phrases as interesting and worth further consideration.

Me: Ok, and when you go into the seclusion room, what do you do?

Tattoo: Finish off my self-harm...and then sit down...and calm down.

Me: Ok. So when you say you finish off your self harm, does that make you feel better to do that? Is that something that helps you calm down?

Tattoo: Yeah

Me: Ok, and you need to go into seclusion to do that?

Tattoo: No, that's where they put me and then I carry on doing it. And then I stop

Me: Ok. Can I ask how you self-harm?

Tattoo: Head banging, scratching myself, tying ligatures...

Me: Ok, so you've mentioned tying ligatures. Do the staff maybe do anything to try and stop

you doing that when you go into seclusion?

Tattoo: Put you in restraint and cut it off.

Me: Do you ever have the unrippable clothes on?

Tattoo: Yeah

Me: And what are they like?

Tattoo: Heavy [chuckles...becomes louder] I tell you what they are so heavy. God I drown in

them. So long.

This particular interview at Host Site 1 with Tattoo was interesting as she seemed to find talking about this quite amusing. She did not appear distressed at having to mention these things, but equally did not appear particularly excited either within the interview process. She seemed to find it quite funny and giggle frequently through the interview. Tattoo provided an insight into the seclusion process and did make me consider the role of staff in supporting and even preventing the women around self-harming when they are in seclusion. Tattoo suggested that she believes she is put in once she has begun to self-harm and this will be explored a little in relation to the written documents relating to her care and treatment to see how this triangulates with the interview itself.

Tattoo's written Patient summary report which I had been given access to detailed incidents of violence, behaviours of concern and seclusion immediately following admission to the ward area. What is interesting is that one incident when Tattoo ties a ligature using socks around her neck immediately following a family visit on the ward. She is reported to have told staff that doing this is "her way of communicating her needs to staff". There is no mention of how staff responded to this, one can only hope and presume that this is now featured within any risk assessment and subsequent care plan relating to Tattoo and her self-harm. I was assured by the RC, Dr Sand, while conducting the interviews at Host Site 2 that women were involved in writing and seeing the care plans that are written about them so that they understand staff responses and approaches to the women and the way they present. Tattoo is also an example of types of self-harm that perhaps occur more frequently in the female population, based upon written evidence and also my own observations from working within these settings. Tattoo will tie ligatures and do this in front of staff. She will reopen previous wounds by head-banging and she will swallow items such as pens, often warranting a trip to the hospital. Aiyegbusi proposes that women who self-harm experience their bodies as 'detached' and use them to express the 'non-verbal narrative of their traumatic history' (Aiyegbusi, 2002:143). My own experiences are that I have witnessed women self-harming particular parts of their body associated with previous trauma or sexual abuse and in unique ways including burning and cutting. Self-harm is described by women as a 'release' from mental pain and as a way of communicating this pain (Harker-Longton and Fish, 2002).

Conversations with Dr Fell at Host Site 1 also concluded that a number of different approaches or measure are taken by staff to address women self-harming including observation levels being increased, belongings being removed and sometimes physical intervention such as holding someone on the floor for a period of time. Dr Fell denied that self-harm itself was a reason to seclude someone but the words spoken by the women tell that they perhaps perceive or understand this differently. It may be that following some of these measures being implemented that women become angry and distressed and then attempt to physically attack staff which may then lead to seclusion being used.

The transcription from Kate at Host Site 1 indicates that she sees a direct correlation between harming herself and seclusion as a safety measure for this.

Me: No, right. So, what makes you have to go in the seclusion room?

Kate: If I, er hit staff or if I get poorly sometimes, I do that sometimes (shows me cuts on her arms and legs) I haven't done it for ages but when I do that sometimes they put me in for my own safety.

Me: Oh ok right. And how's it make you safe if you go in the seclusion room? Do you know how?

Kate: They make me have a nightie on.

Me: Right ok

The interview with Cap and Sweet also showed that at times they felt as though seclusion may be a

punishment for self-harming.

"you cut your arm once...they put you in seclusion" (Sweet)

Contrary to these conversations which took place at Host Site 1, at Host Site 2, Karen contradicts

ever being placed in seclusion due to self-harming. She categorically states that she doesn't think

anyone is put in there for hurting themselves, only other people. However, she does give some

interesting insight into self-harm and the risks that may pose to the women while in seclusion.

*Me: Is there a toilet or a shower in there?* 

Karen: Yes

Me: Do you use them?

Karen: Depends, if I need the toilet, cos we're not allowed toilet roll. Some people swallow

it.

Me: So this might be a bit of a personal question, but how do you make sure you're dry or

clean after you've used the toilet then?

Karen: We ask for it....but we only get like two or three pieces. I tell you its not easy to do it

with that (laughs).

Me: And are you able to wash your hands after you've done that?

Karen: Yeah...no soap though.

Me: No soap, right. What's the reason for not giving you any soap?

Karen: People can drink it.

Karen is quite calm speaking about this. She does not portray distress or display any outward signs

that she has been affected by this. She does seem a little amused by the concept of struggling to

clean herself properly with limited amounts of toilet paper.

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In contrast to this at Host Site 2, Emma identifies as seclusion being the one thing that helps her to calm when she is extremely distressed. She describes cutting herself and banging her head repeatedly prior to and when she is in seclusion. She reports that when she is needing seclusion it takes around 11 staff to hold her and to bring her into the seclusion room. She describes where these people go on various parts of her body. When in the seclusion room Emma will put herself into the strong clothing, designed to provide safety from ligatures and clothing. Emma's interview is at times difficult to understand because of her speech difficulties.

Me: So, Emma. The first question is just "what is it like when you're in seclusion?"

Emma: So, like, I cut myself, with bits, hitting my head on the wall and [can't make out words] my leg.

Me: So do you do that in the seclusion room or do you do that before you go into seclusion?

Emma: No, before, so the blue room is where I go when I do it.

The interview with Tattoo above mentions the "unrippable" clothing. The Code of Practice (2015) refers to this as "rip-proof". Some of the women referred to it as "strong" clothing. Eleven out of the fifteen participants told me they had been put into this to prevent harming with ligatures at some point in their lives when in seclusion. Celia at Host Site 1 echoes the words of Tattoo as she describes them as "green with squares on" and that the women could wear either a dress or shorts or trousers. She tells me they are "massive" and long and very uncomfortable. Incidentally Celia did not wish to be audio recorded so her interview was written in note form by myself as she spoke and not always transcribed verbatim. The concept of the rip-proof clothing and its potential effect on women during seclusion will be discussed a little further in the next chapter.

Dr Sand discussed their belief that some of the women may feel a degree of embarrassment or shame which may then prevent them from leaving the seclusion room more readily and while this was not necessarily corroborated by the women using words such as shame they certainly did speak of practices they didn't like and associated with their past trauma or gender. Dr Sand articulated this through the context of fear of what the other women on the ward may say to them of think of them. The women themselves, when this was touched upon during some of the interviews would often not be able to corroborate this or would shrug and say things like "sometimes".

While I had not been finding shame prevalently within the interview data but also wondered whether the idea of shame was too difficult or even abstract for the women to be able discuss with me. It is arguable that anything linked to self-harm and needing to be locked in or wear rip-proof clothing and then be watched constantly would induce this emotion. I was particularly interested if the idea of being ashamed or embarrassed had any direct link with how long it took women to come out of seclusion and return comfortably to the ward environment. Dr Fell believed that shame would be linked to how that person (in this case the woman) navigated interpersonal relationships. They did then discuss how they felt women did use seclusion in more atypical ways perhaps, that they would retreat, sabotage discharge through fear and that their sense of self-worth and self-deprecation was central to the way they may use seclusion. Dr Fell and I discussed how their belief in themselves was self-fulfilling through subsequent violence, aggression and ultimately then seclusion.

# 4.3.3 The alternative to seclusion – what helps me.

As outlined within Chapter 2, the discourse around seclusion began to turn towards strategies for reduction, elimination and the use of alternative approaches around 2010 (Bowers et al. 2010; 2012; Happell et al. 2011). Soon after this work began to form in the public consciousness it also became apparent that the lives of people with learning disabilities detained within hospital settings was something we needed to change (DoH, 2012). Similarly approaches that are built around therapeutic concepts including Positive Behaviour Support began to drive the way in which we managed difficult behaviour in those whose communication, clinical diagnoses and past experiences made them more difficult to manage both within hospital and community settings. As part of the interview process I began to gain confidence in asking the women what they thought might be a better approach to supporting them when they are extremely angry or feeling as though they can't cope. Interestingly the women were not always able to articulate whether an alternative meant an actual alternative to seclusion or a way in which seclusion might be avoided were a different approach used by either themselves, staff or the hospital.

Kate: I think, erm, sometimes they should give you a choice.

Me: Oh, ok.

Kate: Like go into the calming room. Some people get a choice but I don't.

Me: Is there a calming room as well?

*Kate: Yeah just down there [points down the corridor]* 

Me: Is that different from the seclusion room?

Kate: Yeah, its where you can calm down. And if you don't then they can put you in the other room.

Me: And what's in that room to help you calm down?

Kate: Just some seats

Me: Yeah

Kate: I think sometimes they should let us...offer us...calming...what they called?

[Social worker: Quiet room]

The interview transcription above is one example of the women highlighting for themselves what they would like to do rather than use the seclusion room. Kate goes on to describe a small amount of sensory equipment that is available in the calming room and the social worker confirmed that staff could also be present while the women were in there. Kate also tells me that there is perhaps a lack of sensory equipment and that it would be better if furnished better. Natalie in her interview tells me about the difficulties in accessing a calming sensory room that is available but there are approximately six locked doors to go through as it is situated on another ward and therefore this access if often denied. Karen at Host Site 2 corroborates the use of sensory equipment as providing support to calm and links this to using seclusion also.

A number of the women including Julie, Natalie and Tattoo refer to the use of a bedroom as a space where they may be put if there is no access to a seclusion room or if staff are seeking an alternative. Julie says that she feels that a specially designated sensory room would be much better than a bedroom and she acknowledges the benefits of using seclusion when the urge to self-harm is present.

Me: So do you think it would be better to have another room that you can use?

Julie: Yes, a sensory room then you wouldn't be locked in. Staff could go in with you as well.

You could do what you want. That's better than a bedroom

Bjorkdahl et al. (2016) highlight the possibility that the use of sensory rooms within inpatient mental health services could be used to reduce the use of seclusion. This Swedish study indicates that using sensory rooms can support with reducing stress and improve the therapeutic environment on a ward. Interestingly the study also begins to indicate that enabling patients to access the room and sometimes on their own that the power and control usually exercised by staff was relinquished and more self-control employed. The women in my study appear to appreciate an option involving a sensory room but also indicate that the accessibility and availability is at times limited. Julie's comments above would also indicate that there is no sensory room for her to access but she is in Host Site 2 where Natalie indicates that there is a sensory room but on a different ward. The choice and option to embed this alternative may not be easy to implement but the women indicate that they would like this to be the case.

Another area that the women across the two Host Sites indicate as being supportive is the use of Dialectical Behaviour Therapy skills (DBT) and also talking to their peers and the staff that they trust. This last point will be discussed in a little more detail along with examples from the interviews within the next section of this chapter.

# 4.4 The staff role – hierarchy, support and power

Staff undoubtedly and undisputedly play a key role in the women's lives and their experiences of seclusion. The references to staff within the literature review are numerous. Studies are focused on the experiences and attitudes of staff (Happell, 2011; Long, 2012) towards nursing those requiring seclusion and ranges from researching the views of staff about their own knowledge and decision-making skills and seclusion to more critical writing based on research studies conducted by clinical staff themselves and their views on the best and effective treatments for the learning disabled, mentally disordered offender (Lindsay, 2009; Ward and Brown, 2004).

The purpose of this research study was in part to try to add the voice of the women themselves to the ongoing debate around the secure environment and the use of seclusion in particular. It was important that the women were given an opportunity to speak about themselves as independently as possible but from reviewing the literature, determining what was already known about the experiences of seclusion and then carrying out this research I began to realise that the experiences of staff and the women are intertwined and cannot be easily disentangled or be analysed completely independently of each other. This began to be evident when presenting the Cultural Construction of Language theme earlier in this chapter but was also a feature during the interview process, support

for myself as someone new to the women and the idea of the staff – patient relationship was all too prominent in the interview data also. The triangulation of written reports prepared by clinical and professional staff members as well as meant that the staff experience and knowledge was part of the data collection and analysis process.

## 4.4.1 "They" – the professional role of staff in the seclusion process

In interviews, women invariably referred to the "they". This was often mentioned innocently and often said without prior pause or consideration. It appeared significant in acknowledging the hierarchy, the order of things and the expectation of the women that staff are responsible for much of the decision-making. This can refer to the decision-making process such as a doctor or nurse deciding to seclude or mentioning that the woman can't come out until they have made that decision. This is fitting with policy, procedure timescales and requirements by law as well (DoH, 2015). The women seem unaware of this or don't mention that staff have this professional responsibility or perhaps it is assumed that I will know. Their concept of time is also less well defined or certain which can make it difficult to know whether the women are part of the decision making process around when to leave the seclusion room.

The examples given by Cap and Sweet mention feeling mistreatment while in the seclusion room while Tattoo appears to poke fun at the staff and their use of seclusion within her story telling. Gender of the staff is also significant to many of the women. There is a variety of evidence given through clinical reports, seclusion care notes and the staff discussions about what happens prior to the decision to seclude but this appears lost on some of the women themselves, or they don't consider it worth mentioning. For example, there is discussion in a number of the Host Site 1 tribunal reports I had access to as to how some women are held for a long time prior to seclusion and that at times this results in staff injury or presents safety concerns to other on the ward. From the women's point of view they are often put in there without warning or for doing something that would not ordinarily be seen as requiring a last resort including verbal abuse. While some of the women mention being put in seclusion for their own safety, they will then sometimes contradict this by saying they are then using seclusion to continue self-harming or to isolate themselves further.

Codes that have supported development of this as a theme are:

• Talking to staff and the role staff play for support and to calm

- The role staff play in making the women feel powerless, e.g. men holding them or removing their clothes, being watched, the decision making process and the continuous use of the "they"
- Nursing and medical role in prescribing and providing PRN (including administration in injection form)
- Anger management, DBT, PBS plans
- Perception of what staff believe and think about them

My observations and experience also lend some thoughts to this theme and discussion in Chapter 6. During my time interviewing, staff played a pivotal role in support, allowing some women the voice to say no without pressure or perhaps enabling them to say yes because they were present. Staff were able to offer prompt to the process and my overall impression is that this facilitated and enabled the women more than it stifled them (although reflective diaries do question this). This is their world that they are used to and this is the point they are at within their care pathways. Observations were that staff also did not always acknowledge or check the privacy of the women within the interview setting unless I had been accompanied by someone more readily respected, for example the Responsible Clinician or Research manager. While some women, for example, Bethan and Kate at Host Site 1 choose to be interviewed in the informal lounge setting and asked for this to be the case, others (Celtic, Tattoo, Emma) do not challenge this when interrupted during their interview. Some though do use the opportunity to tell me what they think about staff and the staff role in seclusion process (Cap and Sweet, Celia when initially introducing). Some do appear to grasp the opportunity to speak out and others just couldn't.

The "they" also referred to being deferential or demonstrating what appears to be passive acceptance towards the mysterious figures who first of all made the decision to seclude them, and then those who made the decision to allow them out of the seclusion room. While some women (Julie, Tattoo) refer to their own involvement in accessing seclusion such as needing somewhere to go or engineering the seclusion episode themselves, it was never mentioned that the women themselves made the decision or were supported to make the decision to exit the seclusion room and end the seclusion period. When questioned during some interviews with the women why they had spent so long (sometimes many days or weeks) in seclusion they often referred back to the fact that they weren't yet settled and staff said they couldn't. I asked one woman (Natalie) how she felt about this and her response was simply a shrug. The women did not appear angry about having to wait or at least did not express this when asked within interview.

# "They" decide and "they" put you in

When describing the point at which they enter the seclusion room or the decision to use seclusion is made, a number of interviews use negative language aimed at the staff members involved and at times this language was difficult to hear.

"You get shoved in" (Kate)

"They don't give you blankets...and it's a cold room" (Kate)

The interview with Emma within the second host site mentions being held by many members of staff prior to entering the seclusion room (she mentions 11) and that her clothes are removed prior to everyone else leaving the room.

The Cap and Sweet interview at host site one (ward B) is also particularly damning in terms of their views of the staff role around being put into seclusion. They discuss males watching and removing their clothes and also going on to comment that they don't think this is appropriate because of their history and past experiences of abuse. Their perception of the reasons for being put into seclusion is also unique as Cap refers to being put into seclusion for minor reasons:

"you cut your arm once...they put you in seclusion" (Cap)

This interview was interesting as the two women appeared as though they were being given an opportunity to voice their thoughts about the service and their experiences in hospital and whether because together, or whether their actual experience, this was often voiced placing the staff in a negative and perhaps even abusive context. For example, when I asked whether they were able to see outside while in the seclusion room their response was

"no...because they shut the blinds" (Sweet)

During the interview with Kate she consistently refers to the "they". She mentions it first of all when outlining the reasons for being put into the seclusion room.

"They put me in for my own safety"

It is then mentioned again when clarifying how she is made safe

"They make me have a nightie on"

This phrase is interesting as not only does she simply refer to "they" meaning the staff and thereby hinting at the decision making process but also alludes to power and control as they "make" her put

the nightie on. Kate is referring here to the unrippable clothing used to prevent the women from tying ligatures while in the seclusion room and self-harming or even risking their life.

Kate goes on to mention the control that staff have as she perceives it by talking about the fact that

"they" will let her out quicker if she calms down. Interestingly this phrase then appears that the

responsibility to calm down lies with the woman herself or this is certainly how this was phrased. It

is unclear though whether the women knows what it means to be settled. It appears this is

demonstrated from a behavioural point of view, i.e. no longer attacking staff or self-harming. They

do not mention any specific processes or assessment processes that staff may use in order to

ascertain level of risk. At Host Site 1 Celia echoes this perception of seclusion and staff decision-

making when she states that the doctor will come if she is "not happy enough" indicating that her

level of happiness is dependent on her leaving the seclusion room. She goes on to state that she will

sometimes say she is calm just to get out as she doesn't like being in there.

With regards to the process of decision making and the perceived helplessness felt by the women or

lack of control they appear to demonstrate related to then leaving the seclusion room, one interview

from Site B is quite striking.

Debbie refers to being in seclusion for almost a week but then refers to the fact that she is in fact

calm much sooner than this. The concept of time or even lack of understanding around real time is

not the issue to be discussed here at this point but rather that what Debbie reveals is that she

believes she is secluded for longer and not permitted to leave the seclusion room due to the

seriousness of what she did to be put into seclusion in the first place.

Me: No, how long did it take for you to calm down when you went into seclusion?

Debbie: About two or three days

Me: Right...but you were in there longer than that? Ok. Why do you think it took so long to

come out?

Debbie: Cos I did something serious

Debbie intimates that she believes she has been left in the seclusion room for longer than 2-3 days

because she threatened to attack staff while in there. She does not however demonstrate anger or

a sense of injustice at this. This does not come across in either in the tone of her voice or the words

that she uses.

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The women's level of understanding about seclusion and the process of being secluded does not simply vary in terms of why they are put in seclusion but also in terms of what happens while being secluded. This includes processes or the way they are put in to the room. Celia's interview at Host Site 1 demonstrates a lack of awareness of why certain things are done in a certain way by staff.

"They put your head down" (Celia describing being walked into seclusion while being held by staff on both arm)

When I asked why they put her head down she stated that she didn't know why. When I asked the question to the unit social worker later the same day she explained that Celia will often bite and spit at staff during this stage of seclusion and also attempts to bang her head which is reflective of the more common forms of self-harm and reasons for seclusion seen in this population and as shown in this study. Celia did not appear to know why this was done, suggesting that she isn't spoken to during the process, or she is unwilling to speak about this with me.

Another issue which begins to point at potential issues of shame or dignity for the women is highlighted in Celia's interview. Like Emma at Host Site 2 she also mentions difficulties in accessing the toilet during seclusion periods. However, she does not discuss this in the context of self-harm and risk associated with sanitary products and instead mentions that she has to ask staff if she wants to go to the toilet and cannot do this unless her behaviour and mood are deemed settled. She casually mentions that she has heard that some women have in fact wet and soiled themselves while in seclusion. I spoke with the consultant psychiatrist for the unit who told me that on the ward that Celia is on there is no remote locking system for the toilet and that staff therefore need to enter the room in order to facilitate this. They then told me that if the women are still being violent or aggressive, they have sometimes used this opportunity to physically assault staff. This issue was only mentioned by two women on the same ward area and appears to reflect the physical systems in place.

## 4.4.2 Staff support and the therapeutic relationship

The role of staff as support was a powerful part of this theme. Staff often appear as a paradox within single interviews and more generally across the interview data set. The second site, offering supportive and contributing data to themes from the original site data set demonstrated some key examples of this. Georgia, for example not only trusted staff to speak on her behalf and explain why she wasn't "allowed" to use seclusion which gave insight into her own mental state and coping strategies but also allowed staff to articulate the importance of staff in supporting her not to need to

use seclusion in the first place. Ensuring that Georgia had therapeutic staff relationships in place regularly was clearly a key part of her care. Words like "familiarity", "TLC" and "having a laugh" were described as being central to the care of this young woman in order to avoid needing to be placed in seclusion or held on the floor for prolonged periods of time.

Karen's interview also demonstrates the double role played by staff, but perhaps more interestingly, perceived by the women themselves. Karen describes head-banging as being one of the main activities she engages in while in the seclusion room. The question "what do you do in there?" appeared to be interpreted more than once as meaning what behaviour do you display when in seclusion? Karen knows that staff will come in to intervene if she head bangs while in seclusion but says that sometimes she is so distressed she just doesn't care and other times she needs the staff in there. She contradicts herself in relation to being "held" using words like horrible and nice interchangeably. Being held seems to be something that provides support and comfort but cannot ask for this in advance.

Julie from Site 2 makes an interesting point within her interview about the role of staff support and the ability to access that when required. Julie is one of only a few of the women who believes seclusion offers the opportunity to calm and have some needed quiet space and time away from the ward environment. She tells me that sometimes staff are too busy to respond to escalating anxiety and therefore seclusion is a viable option in order to get that support needed to calm. However, she mentions that if staff are available to respond then this is done more positively and immediately, not resulting in seclusion but increased observation levels or the chance to discuss how she is feeling so as to avoid a difficult, perhaps violent incident.

Interview data from Host Site 1 where I was able to triangulate data also with the written documentation about the women and also speak directly with clinical staff demonstrated the emphasis put on the relationship that women have with staff. These interviews presented a little bit differently as the women did not always acknowledge the therapeutic impact of staff although it was clear from observing staff interact with the women, prompt them and also seeing how they worked with them within their clinical written reports that this was present. Some examples of when the women mentioned the staff importance to their experience of leaving seclusion or being in there are shown below.

Me: Ok, sorry, can I just ask you. You know when you're in seclusion do people watch you? Do people come and check on you?

Kate: Yeah they do. They're there all the time.

Me: All the time. And how does that make you feel?

Kate: I'll be honest I don't really care. I'm just sat there.

Me: Yeah, if you could choose...like when you feel like you're gonna kick off? Is there

anything else that would help more than seclusion?

Bethan: Take some PRN and talk to staff

Me: Take some PRN and that would help you calm down...yeah...

Bethan: And talk to staff

*Me: ...and not use seclusion?* 

Bethan: No

When staff refer to security within secure mental health services they are referring to three types. The first is physical, such as doors, keys, staff numbers. The second is procedural which includes policy, processes and much of this governed by the legal requirements surrounding someone's detention and treatment. The third, and arguably the most important is that of relational security. This refers to the safety associated with therapeutic relationships that involve support, understanding and that human element that needs to be considered (DoH, 2010). Relational security is reflected in this sub-theme so we already know that it is an important element in care and has been demonstrated in the language of services for over a decade now but we are hearing this from the women themselves. They are showing us how important it is to be able to talk to staff when they need to and the role staff play in helping them to avoid being put into seclusion.

4.4.3 Male staff and seclusion

This sub section will also link directly into the theme "This is me" relating to the women themselves and their past history and perceptions of themselves in relation to the seclusion experience. However, when interviewing the participants some of the women refer to male staff and this is usually in a negative context. Further supporting evidence from staff refer to male staff as a positive role model for the women and I also observed within Site 1 male staff demonstrate a respectful and supportive attitude to the women they were caring for resulting in the women responding positively

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to the male nurses and health care assistants present. However, some interviews reveal a perception that male presence when going into seclusion was something that they were not happy with.

Cap and Sweet refer to being "shoved" into the seclusion room but specifically refer to male staff within this sentence. Tattoo mentions that "men look at me" when having to have her clothes removed to prevent further self-harm. When referring to having clothes removed and male staff being present, Tattoo uses the word "strip" which feels significant and is an uncomfortable word to hear from the women as this does not reflect the language used when considering the professional language used in the written reports. During their interview Cap and Sweet tell me how they don't think that it is right for men to be present during this time.

Celia in her first interview states that:

"They strip you down...that's horrible".

Celia reveals a sense of indignity at having to have her clothes removed. I ask whether males are involved in the seclusion process she says "occasionally" and then tells me that they look the other way. When asked if the staff talk to her while doing this to offer reassurance or to explain what is happening, she simply shrugged perhaps as though this wasn't the point she wanted to make. Her discussion appears to centre around the shame of having her clothes removed for safety.

In her interview, Debbie echoes the language used around male staff in particular. This interview takes place within Site 2 rather than Site 1.

Me: And how do you get put into seclusion? Can you describe it?

D: One person here, one person there (points to arms and legs at each side) and one at the back of me.

Me: And do they walk you in?

D: Depends who it is. If its females yeah but if its blokes they just shove me down

Me: So if its males they shove you down? Ok. So do sometimes males put you into the seclusion room?

D: Yeah

#### 4.5 Further consideration of the results and reflections on the data

Consideration of the codes and themes that were generated by the first host site, corroborated or added to by the second host site were then triangulated with additional sources of data. Some of this data was based upon knowledge and opinion expressed by various clinical staff.

Clinical staff were not formally interviewed. The data generated from the interviews from the women was my primary source of information and data gathering. The approach outlined by Stake (1995) discusses this approach within his discussion on triangulation. It essentially begins, particularly within qualitative research, with the questions by the researcher as to whether we are interpreting correctly. He advocates the use of triangulation within Case Study research as a valid way to validate findings and to navigate the inferences we have then generated into our data, in this case the themes and codes from the interviews. Stake is one example who summarises that is it important to put that extra effort into validating or supporting key interpretations or important data if this is then going to give rise to recommendations or present the lives of others in a particular way. Denzin (2006) also supports this approach as lending robustness to the research as it will allow subtle influences on the part of the researcher to be checked out at least in part. It also means that we cannot get too focused on what we perceive as key findings if triangulation mitigates any of this as it will at least call for some reflection on the reasons why.

While the following sub-sections are not new data particularly, they are to illustrate further reflection prior to the discussion part of this thesis and also to highlight areas that were considered by myself as important to mention through their absence rather than the experiences the women were able to present themselves during the interviews.

## 4.5.1. Checking the details and supporting the results data

The interviews are the primary source of data, aiming to reflect the feminist framework of this study and ensuring the voices of the women are central to this study. However, Case Study approach allows for more rigorous checking of this data and to capture the context of the environment and systems within which the women receive their care. I was able to sit with Dr Sand and to discuss my initial thoughts about the women and interviewing. Their positivity reassured me that my research was worth-while and they offered unwavering support throughout the research process. I was able to check details such as how long some of the women had tended to spend in the seclusion room if those details had been vague during the interview. I was able to confirm details such as if women

were asleep when a review was taking place then they would then take longer to be able to leave the seclusion room due to difficulty in completing that assessment. The women had often reported long periods of sleeping themselves and this also confirmed my initial interview with Celia who had reported that very issue. I wasn't always sure from speaking to the women why some were provided with rip-proof clothing and some weren't despite apparent similar preclusion to self-harm. Dr Sand was able to discuss these details with me and it often came down to individual risk assessment or the fact that some women who had said they had the clothing were in fact talking about other women on the unit. This certainly reinforced the sense of a shared experience that I sometimes felt when talking to the women as they would frequently refer to the experience of seclusion of someone else, a friend or someone they knew at another hospital previously. I had been getting the impression they often advocated on behalf of each other and Dr Sand was able to confirm the strong bond that many of the women felt. This was then explored where possible within the interviews at Host Site 2 to provide further corroboration.

It was important that I was able to be guided and reflect on my own limitations, within the interview process as well as this, the analysis process. I had made various notes throughout the data collection process and beyond on my own skills during the interview. On some occasions, depending on the woman I was meeting and their current state of mind, I allowed Dr Sand to be present in the interview because we both felt it was the best way to ensure that I was safe but also that the women themselves felt safe and secure with someone they knew well. While I have reflected in the interlinking chapter that this may have meant skewed or missing data, I also reflect that at times it allowed for richer interview data to be generated. An example is Tattoo's interview, where I essentially could not think what else to ask and was resigned to bringing the interview to a close. Dr Sand asked her a question based on my questions previously, our discussions about what I seemed to be hearing and in a way that I had not considered. Tattoo then spoke for a further 10 mins and gave me further insight into her experiences of seclusion. Dr Sand having that knowledge of her meant she could steer the interview so that the right questions could be asked. The question also allowed Tattoo to reveal a little more about the way she communicated and also corroborated the fact that she perhaps masked her learning disability, appearing more able than she may have been. I had read this information but had not been able to act on this appropriately when asking her questions. Dr Sand used language more familiar to Tattoo as well as referring to an incident she understood and could relate well. My questions had perhaps been a little too abstract for her.

## 4.5.1.1 Dignity and seclusion

When reading the clinical reports from Host Site 1 compiled by either a responsible clinician or a social worker I was struck by the absence of discussion around female health and hygiene, particularly in relation to menstruation, menopause or pregnancy and childbirth. There was brief mention if any of the women had given birth previously. Additionally, reflecting on the interviews I had not thought to ask about this in relation to seclusion. One reason may have been that I did not want the women to feel uncomfortable and it may also have been linked to that when I asked about using the toilets and showers within the seclusion rooms that a number of women said they wouldn't use them and the topic had been dismissed by them. However, I wanted to ask about this and Dr Fell mentioned that often if a woman was menstruating while in the seclusion room they could not be offered sanitary products, as they were sometimes deemed a self-harm risk, for example, swallowing. However, they did mention that it was assessed on an individual basis and dependent upon the individual risk profile. Some women were offered an injection to stop menstruation and that this was more on an ongoing basis, rather than just at certain times when risk of violence and aggression may be higher. Yet these factors were not routinely put into a separate care plan for the women.

#### 4.5.1.2 Medication

Many of the women that I had spoken to mentioned the use of PRN, often fleetingly and without much interest. They said things like, "have my PRN" as though this is just normal and part of the process. They also described needing two types of oral medication as a standard part of the seclusion process, usually lorazepam followed by haloperidol when the former did not work too well to calm then down. I asked Dr Fell about this who said that he felt that the use of medication and seclusion were quite often mutually exclusive and "alternative" to each other. Dr Fell felt that it was not always the case that a woman would be given oral PRN and then use seclusion. However, Dr Fell did mention that it was perhaps more common to for a woman to be given rapid tranquilisation in the form of an injection of either lorazepam or haloperidol prior to the decision to seclude. The women did not appear to distinguish this process and it did not seem to be something that felt important to them. Medication is something they take regularly.

## <u>Triangulation example</u>

Triangulation as an important part of the methodological Case Study approach was introduced and discussed within Chapter 3. The reflections above show how additional data sources were utilised in order to refine and consider the developing themes alongside the women's interview data.

Triangulation is then about validating and offering more depth and robustness to the analysis process.

Within this chapter I have highlighted the issue of self-harm as being integral to the female experience within hospital and also its relevance to seclusion. A number of transcription examples from both of the Host Sites were used to present this. The reports I was allowed access to from Host Site 1 also demonstrate the prevalence and sometimes distinctive way in which the women would use self-harm while on the unit. Sweet, for example has over ten different methods of self-harm listed within one of her more recent clinical reports, written by her then Responsible Clinician (RC). These include insertion of objects vaginally, tying ligatures, swallowing foreign objects, scratching and attempting to stab herself using pieces of wood from furniture she has damaged and pulling out her hair. Sweet, along with some of the other women including Celia and Jay are reported to use large amounts of PRN (as required) medication in order to manage their high levels of anxiety and aggression. The word "impulsive" is also attributed to the self-harm carried out by the women in more than one of the reports I read. Self-harm does seem to have a strong link to the use of seclusion which is also identified by the women themselves. However, what the reports show is that levels of self-harm are considered high and requiring multiple staff interventions which may then result in an episode of seclusion or staff entering the seclusion room and using the rip-proof clothing. Sweet's report also tells us that she has used objects associated with her clothing to selfharm including hooks from her bra and various ripped pieces of material to tie ligatures. This is also evident in other written reports about the other women.

Another triangulation example which supported in validating some of the observations around the language used by the women is relating to some of the more complex language they may use but that belies the true level of understanding. In Bethan's clinical report that I accessed it is written that her assessed abilities are in fact "in marked contrast to her superficial appearance of social competence" (written by her Responsible Clinician). This again demonstrates the influence of the institutional language on the women but also demonstrates the need to understand the women prior to interview or when conducting analysis so that these kinds of considerations will be acknowledged.

# 4.5.2 Host Site 2 and triangulation

An HRA amendment granted me permission to access similar supporting data from Host Site 2. However, the clinical staff there were not able to grant me access to their care notes system which housed similar reports and historical information on the women I was interviewing. The offer of a dedicated clinical member of the care team to guide me through some of the research questioning and to offer further insight was also not available at the time of data collection. This through into question the Case Study framework and the sources of data I had planned to obtain. However, what I did receive was continued support from a dedicated research manager with clinical experience who was present for each interview and was able to debrief with me afterwards. Reflecting on this I am divided in my consideration of the impact of this on the interviews themselves. As with Dr Sand at Host Site 1, there were times that this person's own research experience with the same group of women meant that they felt able to add additional questions that I felt complimented mine and elicited more detailed responses from the women. They seemed to at least recognise this member of staff as someone who supported them and they appeared to feel comfortable in their presence. However, I cannot say whether they may have been less willing to discuss some subjects with two people in the room rather than just myself. Additionally, while some women had initially accepted the invite to be interviewed on the medium secure unit at Host Site 2, when I arrived along with the research manager, all women refused to be interviewed at that time and interviews took place exclusively in the lower secure wards of the site. I cannot say if knowing the research manager contributed to this rejection or whether it was myself or just the circumstances for those women on that day.

The research manager did provide me with insight into the ward environments and also knew some of the women through conducting previous research. In addition to this person some of the women chose to have a supporting member of staff with them from the ward during the interview. D's supporting member of staff was able to tell me about her levels of self-harm when Debbie struggled to do this herself, giving the staff member permission to talk to me. The staff member articulated that due to the way in which Debbie self-harms and the support from staff she requires, that seclusion is not usually conducive to her care or recovery. I felt that this insight allowed me to understand the staff-patient relationship better within the context of the individual and the ward rather than simply hearing from Debbie that she tends to self-harm and then held in prone restraint during the seclusion process.

The interview data from Host Site 2 was invaluable in corroborating and confirming the choice and development of themes. King (2004) argues that reading data at least twice during development of themes and cross checking all transcription provides a robustness and makes for more trustworthy data. Using Case Study methodology allowed the interview data from Host Site 2 to be included in the thematic analysis process as a source of data and also stayed true to capturing the experiences of the women themselves, despite a lack of further corroboration from clinical reports or clinical staff. This has been demonstrated through this chapter.

## **4.6 Chapter Summary**

This chapter has moved beyond the initial stages of coding and theming shown within the methodology chapter to then present these results in terms of meaning and interpretation using examples of transcription, reflections on discussions with clinical staff, written data on the woman and my own observations to outline which data links to the themes identified and why as well as to provide evidence of the way in which this has been considered using the Case Study approach discussed in Chapter 3 and using the overarching feminist paradigm to reflect the results in a way that highlights and questions previous ways in which experiences of seclusion have been presented.

Three themes were developed. They demonstrate that we can find new knowledge regarding the experiences of those who have a learning disability. This is because language can often be overlooked when it is more simplistic in nature or when the interviewee finds it more difficult to describe their experiences, either through lack of wider vocabulary or due to difficult subjects being raised. Reflecting on social constructionist theory and its relationship to power (Simons, 2009), this will form the basis of some of the next chapter when I discuss how we can interpret meaning from these themes. What these results are showing is that language is key to forming a deeper understanding of how the institution is able to influence the way the women themselves understand their experiences, that their past history and trauma is key to their clinical presentation and the way in which we respond.

In addition to consideration around language, clinical diagnoses and presentation such as self-harm the results have also yielded further information relating to the way in which women can be supported to avoid incidences of seclusion and to ensure they are not in the seclusion room for longer than needed. The women discuss their relationship with staff and the positive impact this can have. They have talked about how they would like more opportunity to access sensory support when feeling anxious or upset. Within these discussions, the women also focus on some of the

practical issues on the ward that prevent this support from being forthcoming, including staff time, layout of additional quiet rooms and lack of knowledge around whether they can access any of this prior to exiting seclusion.

Examining the interviews and the additional supporting, triangulating data has also shown that women can have a unique experience of seclusion based on their gender, and not solely associated with issues around self-harm or aggression. For example, it has transpired that risk associated with self-harm may reflect on women more negatively than it would on men, although this was not explored as part of the study. The women reported concerns around dignity, washing, hygiene and sleep. This will be discussed in the next chapter, considering how currently our practice guidance does not acknowledge the gender differences that may be present.

#### 4.6.1 Finding new knowledge

Cultural construction and language

The way in which we have identified the use of repeated description through coding individual words and phrases carefully allows us to use the analysis of this to form a picture of meaning behind the seemingly throwaway or even seemingly unimportant. This further highlights power balance and institutional power through the presentation of systemic language. This is new knowledge as it allows us to look beyond the descriptive to enquire as to the reason behind the use of particular words and what that reflects about the environment and the hospital cultural experience of these women. The study highlights the importance of language but at times its misrepresentation of perception as embodied within the institution.

 This is me – Self-perception and what defines the female and learning disability experience

New knowledge embedded within this theme centres around the individual nature of responses and the importance attributed to this. While thematic analysis and identifying supporting literature during analysis enabled a shared gender experience to be identified and to corroborate or enhance previous understanding and writing, it also highlighted that other individual factors contribute to the experience of someone while in seclusion on a secure ward. At times responses were varied and the feminist approach coupled with Case Study methodology enabled that individual experience to be

acknowledged in analysis as well. Individual participants perceived the function of seclusion differently, demonstrating at times a shared perception that seclusion was used to punish undesirable behaviour and to bring and end to difficult behaviour. It was to some essentially self-fulfilling in nature, linked with notions of self-worth. The findings shown within this theme highlight the multifactorial and a-typical nature of seclusion for these women.

### • Hierarchy, support and power – the importance of staff

The therapeutic relationship has long been a feature of the secure service, demonstrated robustly through robust guidance on relational security (DoH, 2010) and planning care pathways (DoH, 2016). This study brings together the possibility of therapeutic and positive interaction through the seclusion experience as women themselves ask for staff to be present, to talk to them and to acknowledge the likes, dislikes and care needs of the individual within the seclusion process. The women at times challenge our legal and accepted notion of the "last resort", requiring the support of staff to understand and support the experience they are having. Therefore, findings of this study are to highlight the therapeutic importance attached to the process of seclusion for these women and that skilled members of staff are key to that experience.

## **Chapter 5: Discussion**

## 5.1 Introduction to the chapter and overview of main themes

The previous chapter outlining the main findings of the study and structured according to the themes presented through thematic analysis (Braun and Clarke, 2021) allowed literature to be threaded through that presentation to begin interpretation and explain why these themes were deemed important. This chapter aims to build on the previous one through using the themes and the context previously outlined to further develop our understanding and apply deeper meaning to them. The themes will be mentioned and referred to throughout so that it is clear how this meaning has been guided. Literature that was reviewed in Chapter 2 will be referred back to along with evidence of further reading to support the discussion and the journey of the researcher in interpretation of the research data and how I have generated new knowledge within this field of study.

This chapter will present a discussion based on the themes identified and outlined through thematic analysis from the previous chapter, drawing on further theoretical perspectives and literature in order to develop understanding and apply deeper meaning. The following discussion illuminates upon and synthesises elements of the analysis captured within the themes and also focusing on the original research aims and objectives. Each theme as identified and presented within Chapter 5 will be expanded upon and discussed in relation to how the women who are the focus of this study experience seclusion within the hospital setting. The themes will be explored within the context of current, additional literature and theoretical thinking in order to ascertain the importance of the findings and demonstrate the impact this study can have on future practice and research. Consideration will be given to practical elements around the care and treatment of women with learning disabilities in secure care but also I will present how important it is to interpret findings within particular research frameworks in order to highlight the gender nuances of this study. The themes will be mentioned and referred to throughout so that it is clear how this meaning has been guided. Literature that was reviewed in Chapter 2 will be referred back to along with evidence of further reading to support the discussion and the journey of the researcher in interpretation of the research data and how I have generated new knowledge within this field of study.

Seclusion is a last resort. The Code of Practice states that seclusion is used because "it is of immediate necessity for the purpose of the containment of severe behavioural disturbance which is likely to cause harm to others" (DoH, 2015: 300). It states it should not be used as a punishment or solely because of risk relating to self-harm. The Code also provides a set of guidelines relating to facilities, furnishings, windows, communication and also heating and lighting. The following discussion based on the three themes determined by thematic analysis in this study seeks to further explore the meaning of seclusion from the perspective of the women themselves. Currently the Code of Practice (2015) is what guides and determines the way in which processes, rooms and reviews are carried out when putting someone into seclusion as well as initiating other restrictive practices including medication, physical holding or restraint and long term segregation. I am seeking to add to the discussion around seclusion and to demonstrate that it is important to consider current research findings and lived experience when policy and even legal guidance is reviewed.

The following sections reflect the themes identified and analysed within Chapter 4 but offer further discussion and interpretation relating to cultural language and the power held over women and people with learning disabilities through our social and institutional constructs that govern the care and treatment they receive. The sections outline interpretation and seek meaning in the experiences as related by the women The importance of past history and trauma as demonstrated through the theme "This is me" is explored further to reconceptualize the seclusion and how the experiences of seclusion is also reflective of power imbalances but how being female and a female with a learning disability has shaped the way in which these women's lives and their experiences beyond the hospital setting is reflected on the way in which they respond within this study. Finally, the theme associated with the importance of the role of staff once again threads the discussion around power, gender imbalance and differences but also the professional dilemma presented between coercion, professional responsibility and the need to care and support these women who show themselves as often passive, ambivalent and at times resistant to the process of seclusion. This section will look to how we move forward, considering policy and legislation, through our understanding of these women and their experiences. While continuing to adopt the feminist framework outlined in Chapter 1 and woven through the thesis I will be able to present these women as a group of individuals whose experiences through the social construction of gender and disability in our society, our secure mental health services and the ward environments are unique. They need to belong, have consistent and experienced support and force us to examine the way in

which policy and discourse around restrictive practices at the very least acknowledges the world in which they inhabit as seen from their perspective.

# 5.2 Part 1 – Talking about and describing seclusion – creating meaning from Theme 1 Cultural Construction and Language

Within the discussion under this section I will build on the accounts of the women as analysed in the previous chapter and look at how this clinical and social presentation of women with a learning disability and their associated clinical diagnoses. This will demonstrate the feminist discourse and Foucaldian view as outlined in previous chapters that incorporates power both within the hospital and institutional setting but also wider society, reflecting the lives of women with a learning disability as demonstrated through their collective experience of seclusion.

### 5.2.1 The hospital and the discourse

The reason for beginning a discussion around the theme of cultural construction of language as shown in the previous chapter is based on the noticeable presence of cultural, colloquial language used within the institutions, primarily by staff and shown in written documentation. The women regularly use terms and phrases that reflect language used by staff and written in reports and care plans. As I did not directly observe many interactions relating to seclusion or care between staff and patients I was struck by this due to my own knowledge and experience of working with women in secure hospital settings. It is also perhaps more noticeable due to the fact the women are generally not very articulate or do not use complex words or sentences within their interview responses, in fact the written reports that I was able to consult in conjunction with the interviews often stated that the women would need staff to use simplified language and avoid the use of jargon, particularly when in attendance at a mental health tribunal or meeting pertaining to their care and treatment. At times during the interviews the transcription was brief, often with just one-word answers to describe something. This was then in contrast to moments when the women use more complicated concepts relating to their mental state or the process of care. Fish (2018) had previously highlighted this point outlining that this general leaning towards inarticulation often made the exploration of gendered differences more difficult to explore in research within the learning disability population. The written evidence that I also used to collect data from also demonstrated a pattern of language outlining the professional viewpoints about the women and their behaviour, their clinical diagnoses and showing how this links to them progressing successfully through the service with a view to

discharge. This is where we need to remind ourselves that we are researching these women's lives and experiences from a feminist perspective "Feminist methodology is mainly concerned about the way knowledge is produced about the social life and how it can be connected to the social realities of women" (Hussain and Asad, 2012: 203). While also concerned with the role of power and interpreting social constructions and discourse that define the lives of women and women with mental health disorders and also learning disabilities, our women are sparingly represented in literature around seclusion as demonstrated through the literature review earlier in the thesis. Following on from the point of written documentation and professional judgement to influence treatment and progress, much has been written about control and power and a gendered discourse relating to women in secure settings has begun over the last couple of decades, particularly in relation to staff attitudes to these women and their behaviour, expectations of those diagnosed with Emotionally Unstable Personality Disorder (EUPD) and tailoring treatment approaches that acknowledge the unique experiences of the female. What is apparent through reading, whether it be critical of the way in which women are viewed is that themes such as the women being manipulative, sabotaging their progression through services and being highly complex are some of the themes that thread through the discourse. This is also linked to the recognition of prevalent clinical diagnoses including emotionally unstable personality disorder, a condition linked to some of these views (Lindsay, 2004).

The Foucauldian view of discourse is strongly associated with the relationship between knowledge and power. This extends of course to the way in which language is used, even imposed within areas of society and culture in order to either enhance or redress a power imbalance (Rojo, 2016; Foucault, 1982). Bordieu also recognises the power imbalance imposed on those such as children within a school setting around the use of language in an effort to offer education and opportunity equally to all (cited in Rojo, 2016: 81). The concept of language, despite the apparent thinness of the data within some of the interviews is important as it clearly reflects cultural norms and to some degree an acceptance of the balance of power as also shown within interview transcription as well as the reports and the recommendations that are made about the women's care and situation (Rojo, 2016).

Another interpretation of the way in which the women reflect language of care, treatment, and the institution, is positive. People with learning disabilities are often difficult to interview and we have many ways in which clinicians and researchers are encouraged to interact including approaches such as simplifying language, using signs and symbols and techniques that bypass traditional talking and writing (DoH, 2010). However, the women appear to have been donated these words and language

with which they can then begin to articulate their experiences albeit within the current social construct of the institution and care provision that they receive. Positioning myself so that my own knowledge and power within the interview process is acknowledged allows for me to interpret their words within a similar social construct and cultural environment through reflection on what I already know about such services and treatment approaches. It also allows for some reflective work to be done on the way in which I interpret their words which involves looking at my own bias and construct of knowledge around the female experience in hospital which can support in making the data more robust (Nowell et al. 2012).

It is arguable that by the women taking on the language trends of the hospital that this simply reinforces the power and knowledge already held by the hospital and the hospital staff. Rojo though, argues that the cohesion brought by language allows for shared understanding and the possibility of those previously not holding the power that they can begin to resist using the tools of that shared language (2017). Foucault (1982: 39) advocated that to understand power we need to understand how "power reaches into the very grain of individuals, touches their bodies and inserts itself into their actions and attitudes, their discourses, learning processes and everyday lives". This theme has focused on the nature of discourse within the hospital setting and the individual experience of seclusion. Other themes identified have focused on the impact of seclusion, showing how it invokes fear and a sense of powerlessness at times by its very nature but also reflects the participants past traumatic experiences and difficult histories

# 5.2.2 The gendered discourse and power

Bowers (2003) points out that it is normal to resist control and power and become angry. Powell (2001) also mentions this. The words associated with women in secure hospital environments historically have included those such as manipulation and control (Fish, 2018; Aiyegbusi, 2002). Equally when we begin to bring in the discourse around people with learning disabilities which links to seminal work such as Carl Rogers' Unconditional Positive Regard concept at the heart of seminal papers such as Valuing People (DoH, 2001) we also begin to find a conflict in a world which begins to steer the discourse around the disabled person away from mention of manipulative behaviour. However, our traditional view of women as more difficult to work with, more intense and anecdotal evidence of this through more robust evidence-base associated with the tendency to diagnose more prevalently with Emotionally Unstable Personality Disorder (a diagnosis held by every single one of the women I interviewed at Host Site 1) gives rise to a discourse associated with negative power and

the urge to control from a staff perspective. These women are in a more unique position in the view society and the hospital hold of them because they are situated at the intersection of disability, gender and social class (Björnsdóttir & Traustadóttir, 2010). To echo the influential and frequently cited Sequiera and Halstead study (2001) discussed in Chapter 2, the pain and distress that is accorded to the female experience in relation to restrictive practice in secure hospital settings is then demonstrated through this power imbalance outlined within the language the women use through the interview process.

The use of the word "they" to demonstrate the hierarchy and power that the staff held in the seclusion power could also be presented with this discussion in mind, as part of a gendered discourse. The women feel shame, a lack of dignity and fear within the seclusion process and these emotions and experiences are then mirrored within the lives of women with a learning disability, what is written about them (Aiyegbuisi, 2004) and the "they" is interchangeably used within the interviews with comments about male staff or those who have medical power over them.

A further thought can be added to this discussion and the use of "they" to refer to those other than themselves. In using they there is a dehumanising and de-individualising nature to it. It others and depersonalises the staff working with them within this context. They are not using the people's name just a homogeneous – they. A high turnover of staff may mean that it makes sense to do this or even an inability to recall names if considering experiences from a while ago. Also, the "they" when considering a power imbalance could simply inadvertently refer to the hospital or the institution of which staff form a key part of that. They are also then including those who set these rules, those who set the structures that put the women into the secure setting and then seclusion. The anonymous nature of they can reflect the system as much as those individuals working within it.

## 5.2.3 Language and power – empowerment and normalisation

Language and power has a double edged quality. On one hand therapeutic modalities or social constructionism and the idea that the women have been "donated" this language in order to be able to better describe their experiences but that this also can mean less authenticity. It is reflective of the culture, it is still their story but they use the words given to them by the institution as well as wider practices within learning disability and mental health care.

Thinking of the responses as contextually situated (Soukup, 2012) we can also look at the work of constructionists such as Stob and Burke who discuss social constructionism and the idea of terministic screens (Stob, 2008). Our language will adapt, be malleable and reflect our reality as well

as deflect or select. The women are in some way a product of their shared experiences within this particular setting and the views held of them by society. They also respond to questioning within context and this is reflected within their answers, particularly those that demonstrate knowledge and maybe some understanding of the system they inhabit and are expected to progress through.

Foucault comments on the use of records and documentation as a way of subjecting people to a process of normalization, what he calls techniques of power (Foucault, 1982). He also talks about how this information is held by those in charge, who can decide how much to filter down to those below them in order to encourage self-governance. Triangulating data from the interview transcription material with written information about the participants from the responsible clinician has allowed me to see this concept in action. This also demonstrates the value in adopting a Case Study approach which allowed me to view written language pertaining to the women that captured the construction of their lives not only within the hospital context but wider than that. Reference to the women's positions within families, the all too familiar sexual and physical abuse that they had endured and encountered in their formative years as well as showing significant issues in them being able to access mainstream education or meaningful employment. I was able to see evidence of them being moved freely between hospital and prison settings and being denied the generally accepted role of mother, daughter or even wife for long periods of time. This is echoing of a traditional view of these women in literature. Therefore this is not simply representative of institutional construction of these women that constituted the theme around language, more a combination of perceived dangerousness, legal apparatus (Mental Health legislation) and medicalised language that combine in the construction process. All of these elements are also present in the other themes and the discussion further on will highlight the cultural construction of the lives of these women that we see under the spotlight of the Mental Health Act. In terms of language though medicalised terminology that are frequently attributed to people and then to women detained within secure settings has been demonstrated through this study and its findings.

The women and their own responses and language often tend to reflect what is already written about them or said about them by those who are responsible for overseeing their care, treatment and progress through a service. Their terminology which reflects terms such as poorly, risky or doing well is perhaps also indicative of our services as addressing change in these women's circumstances as how well they function in order to be able to present less risk to others and society, therefore placing responsibility back on to the individual and their own self-governance. The women report, however, that the decision-making responsibility does not lie with them but when the doctors or nurses decide that they are ready to leave the seclusion room. There is slight conflict / paradox /

contradiction in that the responsibility to calm and its association with progression through a service, demonstrated through the reports outlining frequency and nature of incidents presented to tribunal panels for example is clearly on the service user. They are required to show improvement and there may be a direct link with this and the ability to leave the seclusion room also (Martineau-Cole and Morin, 2013) and yet the results of this study show a reliance on staff to achieve this. It is documented that women can become reliant on the system that contains and treats them (Adshead, 2022) thus being likely to be more reliant on a system to support them to progress rather than understanding the requirement to take responsibility for their own lives. Secure services and even beyond into a prison setting offers safety, routine (evidenced through mealtimes, care plans, activity planning) and also the opportunity to spend time away from the outside world. Adshead (2010) also reports in her work that women will induce violence to influence events and the emotions of themselves and those around them. Therefore, what an institutional system such as the hospital, which holds the power to influence the women's future, does is to attempt to move them on from a situation which is in fact a safe place for them, regardless of their deeper aspirations.

There is a tension between the language used in clinical diagnosis and associated with certain familiar diagnoses in women, such sabotage, complex, the humiliation experienced during seclusion (rip proof clothes) and the desire of staff to be friendly and supportive to the women. This again reflects that power imbalance and those techniques of power that are indicative of conflict between a legislative system and the therapeutic discourse associated with nursing and treating those with a learning disability. From a feminist perspective this is important to understand. Maynard (1994) and Hammersley (1992) writing around the same time argue that feminist research is to look beyond the male dominated quantification of people's lives and the narrative associated with women. This is why they argue that even while using a qualitative approach common to multiple frameworks or methodologies, a feminist perspective allows any distortion associated with common language attributed to the female experience through society and in this case we see this through the common language of the hospital, the policy guiding treatment and care and the hierarchical approach of health review. Allowing these women to speak is at the very least allowing us to add another perspective to our understanding of their lives. Reporting these finding back to the hospitals and the wider healthcare community can allow us to examine women's true understanding of their care, help us to consider how we represent them in documentation so that their vulnerability and their ability to be involved in decision-making are reflected as far as possible. Care providers can explore more fully the meaning behind terminology like being settled, risky or poorly with the women themselves to allow them to articulate to others how they experience their own healthcare and treatment.

Literature which allows us to consider how best to focus on interviewing people with communication difficulties and to enable more meaning from our interactions with those who struggle to articulate verbally what they think or what they feel is also useful to discuss how best to try to reconstruct this potential power barrier within language. Epstein (1987) refers to the need to find meaning in inarticulation and while this is true of language barriers, it is also important for those who cannot understand or process how they feel also. A study by McCarthy (1998) referred to the real-life examples she had encountered within her feminist research allowing the researcher to begin to empower the interviewee by being able to understand how certain words and phrases perhaps hid something more meaningful. Within the findings I refer to the casual nature with which the women sometimes responded to difficult concepts, or difficult as interpreted by myself. These included being physically restrained, self-harming prior to and during episodes of seclusion and previous traumatic incidents in their lives. I coded this as being significant due to the surprising response I had and the frequency of examples. This demonstrates a process of normalizing their lives and experiences within the unique hospital culture and the types of background they have had yet there is literature pertaining to researching the lives of people with learning disabilities showing this inarticulation can bely a different answer or meaning. This quote from DeVault (1990) is evidence of that difficult to talk at length but demonstrating deeper meaning in a different way

In many instances, "you know" seems to mean something like, "OK, this next bit is going to be a little tricky. I can't say it quite right, but help me out a little; meet me halfway and you'll understand what I mean." (DeVault, 1990: 99).

This shows us that the women are relying on researchers to be able to interpret what isn't said, either because they find it too difficult to discuss topics or because they don't have the language to discuss things in more detail. Researchers should be aware that they could begin to make suggestions to women or other vulnerable participants that they make take up and confirm as being true for them or at times go on to contradict. When this happens during interviews of this type it is the importance of realising the positive power that can facilitate them to speak a little more rather than simply accept what a researcher is saying to them. This is a feature further explored within concepts such as language codes and linguistic deficit theories whereby we not only see a power dynamic played out in discourse between those who are socially placed more powerfully than another (Hassan, 2002: cited in Jones, 2013) but also those such as Hassan (2002: cited in Jones, 2013) would also argue that interdependent relationships within an interview process also mean that implicit meaning is often threaded throughout those discussions. Jones, though critical of this particular theory from a social positioning point of view does acknowledge the importance of not

making academic assumptions regarding language so that interpretation begins to look at the implicit and the context beyond the language itself (2013: 174).

# 5.3 Part 2 – Reconceptualizing seclusion for this population – creating meaning from Theme 2 This is me – The past, the present and the future of women in secure care

I chose This is Me as a title for a chosen theme around the women in my study within Chapter 4 and this was to reflect their responses encompassing messages of abuse, trauma and self-harm and this is often the way in which this particular group of people with learning disabilities have been and continue to be defined. The women in this study are a little different from those mentioned in the paragraph above. They are locked up, deemed violent and constantly have their risk to society formally assessed. We struggle to place them back into society in line with the Transforming Care agenda (2012) and due to their seeming ability and the previous way in which they lived prior to hospitalisation they are deemed less worthy of the sympathy and the airtime.

Therefore this theme represents something different for and to these women. Their lives are constructed a little differently. During this research study and in some previous studies (James and Warner, 2005) they have shown themselves as vulnerable, prone to violence and aggression and using coping strategies that include self-harm, sabotage of discharge and treatment progression and requiring significant emotional support from both their peers and staff. The nature of the services they are detained within often means moving away from family or childhood friends and therefore that support structure is remote and not present every day. Some of the women are mothers who do not see their children or have elderly parents unable to visit if the women are placed too far away to make visiting and travel easy. The following sub sections represent the results shown in the previous chapter that form this theme and a look at the way in way women appear to use and interpret seclusion based on these findings.

## 5.3.1 Past trauma, dignity and self-worth

Rip-proof clothing is a feature of using seclusion when the risk of harm is assessed as being high and associated with using clothing to tie ligatures. The interviews provided a number of responses relating to how the women felt about or experienced being placed into or wearing rip-proof clothing. The rip-proof clothing as a topic brought about responses that I analysed as invoking a sense of shame, anger or humiliation. The responses of the women do not explore how they make

sense of how they feel but they do mention their go to responses such as "horrible", again showing the difficulties as discussed in the first theme of this chapter around articulation. The data demonstrates how it is hard to use the toilet when wearing the rip proof clothing and how ill-fitting and restrictive the clothing is, again at odds with some of the issues of dignity associated with the female experience of seclusion. The rip-proof clothing induces feelings of shame and also paranoia that other are watching.

This discussion is to highlight the issue of the possible depersonalisation that occurs with the women that pervades a sense of degradation and continues to fuel the women and their low sense of selfworth that was discussed with me by staff when the women are in seclusion. Phillips (2005) discusses how being secluded may be construed as a means of being punished. While being put in for self-harming, or not behaving in the appropriate manner are reasons women identify as why they are put into seclusion, the experience itself, if undignified, humiliating and frightening could also be linked to this picture. A lack of access to personal hygiene products sustains the argument that the experience once left in seclusion is one that some of the women perceive as punishing and linked to behaviours of self-harm and their gender. This is reinforced by mention of not wanting to use the shower, the dislike of being watched and the lack of activity and pleasant environment shown by the continuous references to there being nothing to do or nothing but a mattress present in the room. The women can see the link to this and risk but are not always articulate as to whether these rules apply to them because of individual risk. They often appear to speak on behalf of their group and do not refer to individualised care plans and risk assessment. The women certainly identify as belonging to a particular group of individuals who are treated differently but also need to be treated differently as they relate their stories with an air of ambivalence but with care to mention their pasts and their histories and how this can make their experience in seclusion a difficult one.

Host Site 1 allowed me access to clinical notes and reports relating to each of the women who had agreed to be interviewed. Some of the reports highlighted individual difficulties experienced within early adult life and childhood, often relating to sexual or physical abuse by a family member or partner. More than one of the women had had a child and not been able to care for them, resulting in the child being brought up either in foster care or by another family member. However, rather than focus on the individual data once again here it is important to acknowledge that this feature is important to the lives of women, and these are women who are more vulnerable due to their learning disability and all the inequalities and challenges that that brings (Emerson, 2011; CQC, 2020). Once again this data and the way it corresponds to the way in which the women experience

the seclusion room outlines the role that trauma, pain and their personal histories once again dominate many experiences within the hospital environment as shown through the literature review conducted near the beginning of this study (Powell, 2008; Aiyegbusi, 2020).

This kind of data demonstrating a link between traumatisation and certain restrictive hospital practices is not new or particularly illuminating but it does confirm previous findings (Fish, 2015; James & Warner, 2005) and some suggested alternative approaches to managing violence and aggression in these women rather than the seclusion room. Murphy and Wales (2013) cited a CQC report as referring to the "wrong use of seclusion and Long -Term Segregation" (2013: 33) to show that the reasons for making the decision to seclude someone can at times fall outside of the accepted definition of seclusion and therefore when it should be initiated. The interview data as shown in the previous chapter corroborates this as several participants mention being secluded due to self-harming, threatening themselves or others or due to the length of time staff have been needed in order to hold someone in restraint and then seclusion has been instigated following this. What we must see here is the link between that and the nature of the female experience.

When asked the reasons why women are placed in seclusion some women noted that they use it to have time away from the ward. There appears to be a perceived choice or point of control that the women possess. Women suggest that needing time to be away from the busy, sometimes overstimulating ward environment is essential and the idea of seclusion as a last resort is not even factored into this. This corresponds triangulating data within written reports and case history evidence and the suggestion that these women may use seclusion atypically and this paradox that their history and the way in which they cope with managing difficult emotions and relationships means that seclusion is often a degrading and difficult experience for them, but they also want that private time and space that being secluded enforces on them. Some interviews even mention that seclusion is good for some. High levels of self-harm and persistent threats of violence would lead to enhanced levels of observations from staff, removal of personal belongings for safety (DoH, 2015) and seclusion is reported by some women to allow time to be alone or to resolve self-harm.

#### 5.3.2 Sensory support and the alternative to seclusion

A number of the interviews demonstrate that the women have been encouraged or facilitated previously to use alternative ways in which to manage their behaviour, thoughts and feelings and hopefully then to avoid being put into seclusion. The Mental Health Act Code of Practice (DoH, 2015) is clear about the aims of seclusion and when it should and shouldn't be used. Some of the women indicated in their interviews that they would like changes to the experience of seclusion that mirror a low stimulus, sensory supporting environment. Some go so far as to describe the kind of equipment they find will help in calming them down. Both Host Site 1 and 2 had facilities or rooms that were invariably referred to as "the quiet room" or "the sensory room", to show that there was a place that the women could go to if they needed time away from the busy ward environment or needed this kind of environmental support to manage their aggression and anxiety. At Host Site 2 the member of staff and one of the women within their interview indicated that they couldn't always gain access to the sensory / calming room due to where it was located on one ward only. Another fundamental difference was that the room that may have equipment the women could use to calm would allow them to be with staff rather than completely on their own. It is important here that we can make the distinction between an area that might be designed to support the women when they begin to feel anxious and need either some time to calm away from the perhaps busy ward environment and the last resort that is seclusion. A sensory or calming room would be where they can speak privately to staff and where staff could support them to initiate some of the coping strategies and skills they may have learned and be encouraged to use before anyone is physically assaulted or requires removal from the environment for safety purposes against their will.

Yet while the discussion relating to finding and using alternative approaches to seclusion, including "time out" and positive behaviour support approaches (Emerson, 2011) is being articulated by the women in their interviews are these reflected in what is currently being used or advised within literature? We should discuss whether this fits with previous findings or whether they are expressing something that is unique to them and their experience.

Martineau-Cole and Morin (2013) discuss service user perspectives as well those of staff when implementing seclusion and other restrictive practices such as physical restraint. They mention that the participants in their study highlight the use of sensory based approaches such as using a ball to throw or to squeeze. Jones and Kroese (2007) and Fish and Culshaw (2005) also highlighted this. This is consistent with some of the findings in this study where some of the women discuss in some detail what they use to calm, including bubble tube equipment, lights, music. It also echoes other recent literature where both staff and service users appear to benefit from the use of sensory

equipment when highly aroused and agitated (Wigglesworth, 2016). However, what is interesting is that in other interviews women discuss additional ways they prefer to calm including speaking to staff or having access to personal possessions including photographs and other items. While some women actually ask me why there can't be sensory equipment or music of choice available in the seclusion room, others state that the seclusion room is not the place that they would want to access this. This reflects the nature of seclusion as the last resort following a decline in mental state and risk posed to others or themselves. The discussion around alternatives therefore varies. While a number of the women mention using an alternative venue and sensory or calming equipment, some of the women wonder why they aren't able to go in there rather than the seclusion room, others see that when they are in seclusion it is because they are unable to cope or to calm using these other kinds of methods and see a distinction in the level of anxiety, aggression and state of their mental health during these times. It is therefore important that we are able to highlight the nature of the alternative as either a preventative measure involving de-escalation techniques or as an actual alternative to using seclusion when someone becomes violent and poses an immediate risk to others. This variance in findings indicates that an individualised assessment approach to seclusion is important and once again, referring back to the level of learning disability and understanding these findings may also highlight the importance of exploring with groups of women and men alike, what they understand to be the purpose of seclusion. With narrative and discourse varying this can lead to a sense of injustice as well as significant disempowerment, already a feature of women's lives.

While this finding within my study echoes some of the work from wider research on the use of seclusion and the alternative such as Bower's (2010; 2012) suggestion of the concept of "time-out" it is interesting that the women are more focused on the need to have staff with them and not be alone when they are wishing to use a sensory room. What makes the women's interviews around using alternative methods rather than seclusion meaningful is that they repeatedly highlight the support of staff as vital for anything alternative to work in preventing an incident of seclusion.

#### 5.3.3 The significance of self-harm and how seclusion is utilised

The Code of Practice (DoH, 2015) states that "Seclusion should never be used solely as a means of managing self-harming behaviour. Where the patient poses a risk of self-harm as well as harm to others, seclusion should be used only when the professionals involved are satisfied that the need to protect other people outweighs any increased risk to the patient's health or safety arising from their own self-harm and that any such risk can be properly managed." (2015: 300). The Code of Practice is

stating that self-harm alone cannot be used as a reason to use seclusion for someone. The women report that this isn't always how they perceive it. Women state in their interviews with me that they feel they are put into seclusion solely because they are hurting themselves. The results chapter showed that self-harm is a constant feature of the women's lives. Literature also supports this as something that women and also people with learning disabilities and poor mental health experience or use as a way of coping (Lovell, 2004; Levine et al. 2018). Some responses indicated that the women identify their ways of self-harming as personal to them, even referring to it as "my self-harm". Self-harm is a key feature of the women's experience as women and its type and prevalence often unique to the female experience. It will reflect the reason that more women than men are granted a diagnosis of Emotionally Unstable Personality Disorder and now identified as a unique subgroup due to the characteristics often associated with key features of this disorder (Karsten et al. 2016).

The significance of discussing this further within this chapter is based on demonstrating the results of this study within the context of changes in care and treatment approaches as well as societal approaches to self-harm. Dialectical Behavioural Therapy (DBT) is an example of how many care providers are now approaching the treatment to the way in which these women among others clinically present (Thomson and Johnson, 2017). The women I interviewed at times refer to using their DBT skills and one of the key features of this therapeutic approach is to offer validation for certain feelings and behaviours while offering alternative ways of managing these. Written reports corroborated DBT's positive effects through demonstration of a reduction in seclusion incidents, acknowledging the emerging ways in which their behaviours of concern were being supported and managed more compassionately and effectively. However, what this also served to highlight in some cases was the direct link that the women themselves made between being calm, their ability to use varying techniques to calm and the likelihood that they would be placed in seclusion. They continued often to associate their self-harming tendencies with a risk of being placed in seclusion. DBT and further meaning will be discussed in the next sub-section also. This begins to highlight the difficulty in using the Mental Health Act Code of Practice (2015) and ensuring that it is followed through local policy and process as it becomes more evident that women, self-harm and seclusion are so inextricably linked. This dichotomy of professional roles will be explored a little further into this chapter when considering the way in which policy guides our way of working with women.

#### 5.3.4 Moving towards a more meaningful life

Higgins contingency management concept developed in the 1980s discusses the concept of a rewards system in relation to those battling drugs addiction (Higgins, 1991). This approach advocated that those receiving material incentive not to use drugs were more likely not to do so. Within forensic mental health treatment in the early 2000s the Good Lives Model began to emerge as a strong theoretical approach to treatment for those who had committed sex offences. The Good Lives Model based itself more on building a better alternative for those who had committed offences or were at risk of doing so (Ward and Brown, 2004). The essential premise was that by identifying areas that would target some of the social and more dynamic risk factors including poverty, relationships, employment, education and well-being that people were less likely to offend if those areas of their lives were improved, thus acknowledging the impact of distress, abuse and a difficult life.

The language that pervades throughout the data that I collected as well as through literature around gender and the use of seclusion and other restrictive practices may be seen as punitive or at times judgemental in nature. The acknowledgement of the trauma and the histories of these women is evident. The use of approaches that also acknowledges and supports this is also apparent including supporting women to employ Dialectical Behavioural Therapy skills when they begin to feel anxious or angry which may then lead to violence and then to seclusion. However, while the trauma and sexual abuse histories of these women is undisputed and certainly written down, the discourse often employed tends to focus on ensuring the women can manage their feelings around it, that they are able to function in a way that allows them to engage safely in society and therefore to thrive and enjoy life more and when they cannot there are measures such as removal of belongings, close level observations, restraint and seclusion. This was explored within Part 1 and this chapter in relation to language but is being applied here to highlight the way in which management of female violence and subsequent restrictive practices are considered in terms of the female experience and clinical presentation.

There is evidence that the use of DBT skills is beginning to enable groups of individuals falling into particular categories (those with Emotionally Unstable Personality Disorder, eating disorders, self-harming behaviour) to better manage their own behaviour and the emotions associated with it. The dialectical dilemmas identified by Linehan (1993) highlight many of the difficulties that this group of women together experience. Those linked to emotional vulnerability, passivity and self-invalidation. Also, those studying the effects of DBT in groups who are also subject to coercive and controlling measures such as a patient with an eating disorder (Wisniewski and Ben-Porath, 2015) are beginning

to highlight that DBT using contingency management approaches, patient involvement and contracting is working well to reduce undesirable and risky behaviour. While this certainly continues to put an element of responsibility onto the individual it also allows them to see the effects that employing approaches that support them to calm or respond more positively to others can have. However, it is not always easy to ascertain how these DBT skills are best adapted given that women with learning disabilities in secure settings have been reported to need the support of staff and struggle to mentalise why they may feel the need to behave or respond in a particular way to emotions and impulses (Johnson and Thompson, 2017; Adshead , 2010). This study has continued to highlight this dilemma in the application of self-management and the use of the DBT approach.

Ability to manage behavioural responses is further monitored through institutional processes such as Managers Hearings and Mental Health Tribunals all outlined within the Mental Health Act 1983. As reports are prepared for these, the women's progress is demonstrated through adherence to medication, frequency and intensity of incidents that result in restraint or seclusion and then ultimately treatment and whether the women should stay in hospital are recommended or defended. This is of course in line with professional and legal accountability to keep both the patient and the public safe. Adler and Longhurst (2002), also referencing work by Foucault (1979) and in particular his principles of correction, identify that while focus remains on correction through transformation or change that there is the alternative discourse on which the experiences of the person themselves (in their case prisoners) are prioritised. This is not the focus of Adler and Longhurst who choose to focus their discourse on those with the power.

Recent studies like those of Van Damme et al. (2017) and Pflugradt and Allen (2019) have begun to focus and apply the Good Lives Model as a workable theoretical framework for forensic treatment approaches used for women. Approaches already researched and applied in the context of gender and the female experience include the aforementioned cognitive behavioural approaches and the therapeutic relationship (Long, 2012). The studies are showing a promising beginning to applying a theoretical and empirical approach to treatment for women which has at its core the belief that high quality of life is associated with recidivism and the ability to manage impulsive and aggressive behaviour which may result in offending. They are beginning to demonstrate that focusing treatment on the future for the person and the potential of an individual, rather than simply acknowledging the past and current behaviour means that these women are more likely to move beyond the forensic care system and live a more meaningful life.

#### 5.3.5 - Women with a learning disability and their lives - the ability to move on

In March 2022 the CQC published their progress report on the recommendations made in 2020 in their Out of Sight – Who cares? report. They reported on how people with learning disabilities and autism continue to experience hospital care and incidences of seclusion as well as other restrictive practices. Their progress continued to highlight that people with learning disabilities continue to be held in hospital for long periods of time, unable often to plan for their future and leaving the hospital and that people continue to be subject to over-use of chemical restraint, physical restraint, seclusion and long-term segregation. As you would expect a focus is often on workforce development, workforce numbers, lack of appropriate community services and funding for particular projects to explain not being able to meet recommendations made in 2020. I have used this example as it captures the national picture for people with learning disabilities. Our women, in addition to their gender and the nature of their detention in secure hospital have an added difficulty in that they are learning disabled. We continue to see inequalities across the learning disability population in the UK both in terms of health and also life opportunities. These women are not only in a category with a lower uptake of access to GP health checks and screening compared to the rest of the population (Walker et al. 2016) but are also detained within a hospital setting where access to primary and even secondary care services are impeded. The LeDeR report in 2021 (NHS England, 2021) found that people with a learning disability including those within secure hospital settings were more likely to be given psychotropic medication that was beyond therapeutic dose and have difficulties with identifying changes in physical health.

Seclusion highlights some of these risks in that women report spending longer periods of time on their own and using more than one medication to calm. Medical reviews are there to support checks of physical health by both nursing and medical staff, but the nature of seclusion often precludes the women from being actively involved themselves in this review as they report being woken to be reviewed or being reluctant to allow people to check them physically. Their dependency on others to understand their health and enable access to the health care systems they need is also shown through that passivity that is evidenced through the time they spend in seclusion. We have seen evidence through this study and literature that these women often reject or are even denied a typical female experience when explored within the context of restrictive practice (the use of male staff to restrain, injections given to prevent menstruation in the seclusion room, no mention of menopausal symptoms within clinical reports relating to behavioural disturbance). This is mirrored through the distinct absence of gender or disability being mentioned within legal policy and guidance (DoH, 2015). The voice of these women is currently silent within the debate around

the use of seclusion and all of these factors are part of the experience of women although seemingly not always of these particular women. Circling back to the discussion highlighted through this section of the chapter that focuses on what is unique to being female but more importantly, unique to being female within a secure service, it is emerging through this study that the women not only have a unique experience in comparison to male counterparts generally across secure services but also in comparison to other female experiences outside of the secure environment.

#### 5.3.6 – A sense of ambivalence

The women while distressed in the seclusion room are also reporting that seclusion can offer them that time to be away from the ward environment and as discussed in Part 1 of this chapter and within Theme 1 within Chapter 4, their consideration of seclusion is often underwhelming. While I have alluded to their possible lack of understanding in relation to seclusion being used as a last resort, it would also appear that they in fact require the seclusion room to be used atypically. They do not always need sensory equipment that they might value and benefit from outside of the room and use the time to sleep. The overwhelming association with the seclusion room relates to "their" self-harm and while for some this means that every effort is made to prevent a seclusion incident and find another alternative, others appear to value that space. There is also a sense at times of notoriety associated with being in seclusion either demonstrated by the way in which women describe engineering going into seclusion or relating the experiences of those other than just themselves. This is not to devalue the reporting of how difficult many of the women do find the experience of seclusion but going back to the literature review in Chapter 2 and the work of Crawford as far back as 2001 already we knew that women were likely to use self-harm in order to elicit the required support from staff and to gain what they needed, something now more recognised within aspects of treatment but not yet reflected in the societal or political view of seclusion.

The debate around alternatives or the elimination of seclusion continues. Our concern about the lives and experiences of people with a learning disability within secure hospital settings is also very real and prevalent within current literature (CQC, 2020). The "last resort" nature as outlined in our legal guidance also ensures that we continue to consider seclusion as something that is to be considered seriously before utilised and that we must observe strict processes and procedures around this as the staff that use them. The role of the staff is very important. Staff members are there with and observing the women while they are sitting, sleeping, shouting, attempting to self-

harm in the seclusion room. Importantly, the women essentially often express ambivalence towards the process, either due to this being accepted as a normal part of their lives or because it feels necessary to them and while some of my interviews told me that seclusion should not be used, others did not feel that way. This atypical nature of seclusion is worth consideration and potential reframing of its meaning for some populations while we continue to debate its use not only within the UK but around the world is crucial in representing their views. Adshead (2022) also points out that for certain groups of women, the sense of social isolation runs deep and that it is often our sense of professional duty as staff and the bureaucracy that govern process around seclusion that mean we view seclusion and restrictive practice as part of our duty to keep people safe. Therefore this sense of ambivalence that is evident within my study, even when considered within the context of language and difficult issues cannot be viewed through our lens as staff or the researcher. We have to try to understand what it is that the women feel about the use of seclusion. This leads us on to discuss the experiences of the women within the context of policy, legislation and our professional responsibility and role.

## 5.4 Part 3 - Moving forward: the future of seclusion for the women – Creating meaning from Theme 3 The staff role – hierarchy, support and power

The role of staff and their importance to the women was prevalent throughout the data collection process and across both host sites. In some cases staff were looked to for support during the interview, often being able to clarify answers the women gave or provide further information around an answer that was perhaps a little brief. When staff were not present they were consistently referred to. It is understandable that some previous studies around working in these kinds of care environments have chosen to directly compare the thoughts and experiences of staff with those of the patient and the study that I conducted myself (Goulding and Riordan, 2013) seeking to explore staff experiences in working with these women and that initiated this study demonstrated that the two, staff and patient are inextricably linked. This was evident as demonstrated through the choice of Theme 3 in Chapter 4. These findings will now be discussed through the interpretation of the presence of staff, the therapeutic relationship and how we are required to use seclusion within the UK.

#### 5.4.1 The professional role and seclusion processes

The results chapter outlined the extended use of the "they" pronoun within the interview data set relating to the power and authority that staff have relating to seclusion. The women refer to being held, being put into seclusion for safety reasons relating to others and themselves and do not tell me that they are involved in either the planning or the experience of seclusion. This means that they are telling me that staff decide when they go in, for what reason and for how long. None of the women refer to supporting care plans or discussions with staff relating to assessing risk, fitness to leave seclusion and seclusion prevention. There are examples of women reporting using skills such as DBT (Dialectical Behavioural Therapy) or having attended anger management courses but little or no reference to this being applied to their experiences of seclusion although this may indicate a reduction in incidences of seclusion and is demonstrated in some of the clinical reports from Host Site 1. Some staff present during the interviews do refer to seclusion not suiting some women due to their increased risk of self-harm while in there and therefore using alternative methods, inclusive of the positive therapeutic relationship with familiar staff members.

The Mental Health Act Code of Practice makes reference to alternative ways of keeping people out of seclusion. It refers to service-user / patient involvement in the risk assessment and care planning process. It also refers to Positive Behaviour Support planning (PBS). Yet the language is also very much adhering to the decision-making powers bestowed upon the professionals and staff members. For example, with regards to the use of the rip-proof clothing and the risk of self-harming the Code of Practice states "Positive behaviour support plans (or equivalents) should detail primary preventative strategies that will aim to avoid the ongoing need for such restrictions. The patients should be told what they need to do so that they can wear their usual and preferred clothing." (DoH, 2015: 310). It is the phrase "patients should be told what they need to do..." which is striking here. None of the women refer to this kind of discussion or demonstrate an awareness of how they can avoid the rip-proof clothing and also the statement is a little contradictory with the concept that when seclusion is used it is due to extreme and unmanageable behaviour that has put others severely at risk. It also puts the emphasis on the patient to acknowledge and then implement PBS or DBT related strategies in order to avoid something which in my study, the women refer to as degrading, humiliating and something which causes them stress. The emphasis within the Code of Practice on the responsibilities and professional responsibility of the member of staff, either nurses or medical staff suggests a potential difficulty in involving the patient in the seclusion processes. This may be particularly pertinent to the group of women that I interviewed due to the high levels of

self-harm displayed by the women and the frequency with which they require physical restraint due to incidents of violence (Long, 2011).

The Code of Practice also quite rightly refers to maintaining dignity while also placing its guidance on safety for everyone. This includes being able to see someone at all times, having the room sparsely furnished and that doors are robust. The Code also mentions that where possible the person inside the seclusion room should be able to see outside and therefore dependent on positioning and design of windows. The women I interviewed and asked all reported not being able to see outside. They also mention being watched as something they find difficult at times. It is acknowledged that seclusion is outlined within the Mental Health Act and other documents (DoH, 2014) as being a last resort, primarily aimed at maintaining safety and not to be considered as part of treatment.

However, it should also be noted that the women I interviewed as well as other women reflected in the literature have long histories of sexual abuse, traumatic experiences including being punished and controlled and use high levels of self-harm as a way of coping with the way they feel and express themselves. This can appear conflicting to the way in which seclusion is outlined within such documents as the Code of Practice, for example as shown in this section in relation to using rip-proof clothing and the responsibility of the patient to ensure they are not subject to this measure. Monitoring someone who is not likely to calm quickly in seclusion either because of lack of social stimulation, the inability to articulate how they feel and therefore self-harm could mean that reviews deem them too much of a risk to leave the seclusion room and therefore lead to longer periods of seclusion as based on review criteria. The Code certainly acknowledges the potential traumatising effect of being placed in seclusion and the data I collected in my study supports that staff work hard to ensure that they support women before, during and after a seclusion incident as well as ask me to record recommendations they have. However, the language used in the Code of Practice also reflects a robust review system with little room for manoeuvre and an emphasis on the staff authority to make decisions.

The Code of Practice is very clear in its requirements of staff around monitoring the health and condition of those in seclusion. Nursing reviews should take place every two hours but allows flexibility where the person is asleep.

26.136 When patients in seclusion are asleep, provider policies may allow reviews to be undertaken in accordance with a revised schedule which should be recorded in the seclusion care plan (see paragraph 26.147) in order to avoid waking the patient. (DoH, 2015: 305)

The women I interviewed frequently reported sleeping as the one activity they resorted to in the seclusion room. They acknowledge that this may be in part due to medication effects (women often requiring rapid tranquilisation immediately prior to or during an episode of seclusion) or tiredness following a period of high anxiety and "fighting" with staff. Another factor was that a number of the women reported sleeping as being the only thing they could do while in the seclusion room, even once they felt calmer. As legislation and policy advises, reviews can be flexible in order to avoid disturbing someone and also supports the involvement of the person in their review. However, this could mean that the women spend longer than necessary in the seclusion room due to being asleep for long periods of time.

We know that there is literature linking over-medication and use of psychotropic medication in particular to people with a learning disability through the work of NHS England, the Royal College of Nursing and other organisations and their STOMP pledge. This was discussed within Chapter 2 and is pertinent when considering the way in which processes such as those relating to seclusion, segregation and restraint are applied to this population. The language used within documents such as the Code of Practice (2015) and also those aimed at improving the lives of people with a learning disability in hospital care is aimed at improving quality of care and uses language which is important to acknowledging the potential trauma and difficulties faced by those entering seclusion. It is however, by its own discourse around dignity and the boundaries around review timings, potentially ignoring of those experiences that women may have had. Seclusion policy therefore is demonstrating through the view of these female experiences, a particularly androcentric approach to issues such as dignity and the way in which seclusion is monitored, albeit highlighting the importance of seclusion as a potentially traumatic experience.

In addition to the view that seclusion is something to be used carefully and sparingly, alluding to trauma (DoH, 2015; Brophy, 2016; CQC, 2020), during interviews there were examples of trust between the women and staff present or staff being referred to in responses and the way seclusion had been used for them. Women reported that talking to staff was something that can help prevent her being put into seclusion or something that can help shorten the period of time they will spend in there. Equally, the women at times reported valuing the time they spent in seclusion as it gave them the opportunity to talk to staff and have that attention they needed to discuss how they were feeling or to reflect on why they might have responded in a particular way. It is easy to take this perhaps at face value and assume that this is an issue for the women when locked in the seclusion room, however, it also seems to highlight the importance of that therapeutic relationship. This

shows seclusion also as a supportive end point to an experience of extreme anxiety or violence, requiring an additional therapeutic intervention from staff.

The women appear to need staff for safety and support. They rely on them to support with managing their anxiety (Thomson and Johnson, 2017) and using skills they may have been taught via treatment groups or therapy, particularly when unable to manage their own behaviour due to anger or increased agitation. Studies including those by Long (2012) and Happell and Koehn (2011) looking at predictors of seclusion and also the importance of the staff-patient relationship at a time when much literature called for an end to the use of seclusion and the identification of alternative methods to manage people in secure hospital environments discuss how the familiarity of staff was an important factor in supporting people to avoid being put into seclusion or to enable them to calm and leave the seclusion room. The women along with those supporting them in some interviews discuss how talking to staff that they knew or simply having staff that they were familiar with and felt understood them was integral to their seclusion experience being a more positive one.

As well as raising the potential question as to the function of seclusion at certain times for staff (Williams, 2018; Happell and Koehn, 2011) who are attempting to calm difficult and potentially dangerous situations this highlights the importance of the staff member for supporting the women through the seclusion process. A number of the women when being interviewed were recalling incidents of seclusion that weren't recent and would proudly tell me that it had been a number of months or even years in some cases since they had been in seclusion. This would indicate a more therapeutic cultural understanding and positive behavioural response to female anxiety, ensuring that familiar staff worked with them more regularly and were able to positively respond to and deescalate potential situations where seclusion may be used as a last resort.

#### 5.4.2 Prevention and support

Within Chapter 4 the code referring to "they" featured as part of the analysis and this particular theme. The "they" pronoun and its relevance to the way in which the women experience seclusion will be discussed a little more under the next sub-heading. However, the women's responses as well as my own observations and discussions with staff certainly warrants some discussion as the role that staff play in ensuring the women are supported therapeutically before, during and after an incident of seclusion is evident across both Host Sites. Six of the participants verbalise that talking to staff helps them to calm either in order to avoid an incident of seclusion or while in the seclusion room. The observation that staff were actively seeking alternative ways for the women to access

other means of spending time away from the ward or to encourage the use of alternatives that were person-centred to that individual showed a deeper understanding of the way in which the women require support when highly anxious. One of the clinical staff from Host Site 1 and the research support staff from Host Site 2 both highlighted that peer debrief was potentially important for the women following an incident of seclusion, a way of bypassing the shame and sense of isolation. This is also reflected in some literature that highlights the importance of this for both staff and patients following incidences of seclusion (Green et al. 2018). Equally, some research has shown that some of the skills that the women are provided with such as Dialectical Behavioural Therapy (DBT) skills are more supportive during times of high arousal and potential aggression when the women can be shown these by staff rather than needing to recall these skills for themselves (Thomson and Johnson, 2016).

The thematic analysis and results of this study highlighted that some women saw the presence and involvement of male staff when being put into seclusion as negative. Whether this could be proven or corroborated, some of the women perceived that they were inappropriately watched by male staff during the seclusion process. This is also mentioned in relation to the changing into rip-proof clothing therefore requiring the women to remove other clothing. Words relating to putting on rip-proof clothing include "shame", "naked" "horrible". This indicates some of the feelings of the women when required to wear this. The Code of Practice as already mentioned highlights the need for dignity as far as possible but this is not considered within guidance in relation to gender and previous history. While not all of the women mention men, those who do appear to find it traumatising when men are involved in the seclusion process. These are all women who have had to be held for longer periods of time or have to use rip-proof clothing. Ridley (2020) in her thesis highlighted the difficulty that women with a learning disability in secure services may often have in male staff being involved closely with their treatment and the findings from that study indicate these are those staff working closely with women every day within their own environment.

Merineau-Cote and Morin (2014) and Goulding & Riordan (2013) highlight the stress that staff experience when making the decision to seclude someone and often associated with the risk of physical injury to themselves and others. There is little emphasis on gender within the first study but they do highlight the need to feel safe including having someone larger there who can support physically while the Goulding and Riordan (2013) study refers specifically to the experiences of nurses working with women in learning disability services. Happell and Koehn (2010) while determining in their quantitative Australian study, that females were less likely to be secluded than males, the reasons often linked to actual violence rather than threatened violence. This would

support the concept of seclusion as a "last resort" for female service users but would also indicate that perhaps it requires larger numbers of staff and at times staff that can support with the physical aspects more easily, including men, then resulting in a more difficult experience for the women themselves. Do the women view male staff putting them into seclusion, which they at times perceive to be more physically aggressive) as a punishment based on their previous experiences with men? That is not a question answered by this study but raised by some of the responses of individual women within their interviews and may be important for future research to explore. This is a point that was certainly considered when reviewing previous studies and literature earlier on in this thesis and was outlined by authors including Holmes et al. (2004). Seclusion as a punishment has been previously mooted within a gendered context and the context associated with the male member of staff here would also echo our already established knowledge relating to trauma, abuse and previous history (Ali and Adshead, 2022).

Swinton and Bell in 2002 questioned whether the debate around seclusion should take its focus away from elimination and tight processes by beginning to talk therapeutically around the use of seclusion and how it can be made less stressful for the individual. This is earlier on regarding the use of seclusion and the discussion and debate that followed over the next decade and the aim around reduction of seclusion. Interesting comments from Swinton and Bell (2002) relate to the belief that seclusion is effective when violence is imminent which appears maybe contradictory to the concept of seclusion as the last resort as stated in the Mental Health Act Code of Practice. However, what this does allude to is the idea that seclusion is inevitable at times, although there is no particular mention of gender here in this there is that debate should shift towards how seclusion can be used more effectively and incorporate the needs of the individual. This is interpretation on my part, founding on structured clinical judgement and experience. This piqued my interest due to the concept of seclusion as a chosen and needed end point for the management of violence and aggression, as well as raising some interesting ethical questions relating to robust research as Swinton and Bell echo the induction prevention paradox (Heyman and Godin, 2013) arguing that to really ascertain the effectiveness of seclusion we have to manage behaviours in alternative ways and measure the outcome. I am commenting on this to link in with staff decision-making and its consideration within the therapeutic milieu. The participants in my study indicate that this is an integral component of their seclusion experience.

#### 5.4.3 Working together to find meaning

The title of theme 3 in Chapter 4 refers to hierarchy and power as well as support. When introducing myself to interview participants it was important to highlight that I was a learning disability nurse and in some of the interviews this did appear to elicit a level of trust and understanding. This is fundamentally part of a feminist approach to research and the principles adopted by this study (Hussain and Asad, 2015). This trust and shared knowledge has been shown in the results chapter by the implicit way some questions were answered without further explanation being required. However, what also emerged throughout the duration of data collection was the unequivocal and open hierarchy that we attribute to staff and this is directly linked to the process of seclusion. The hierarchy is open within these organisations where simply by openly knowing and announcing nursing bands, job or role title we immediately attribute a level of power to that person.

Organisations inclusive of the NHS also adopt this hierarchical approach as we immediately capture what someone earns as soon as we are aware of their job role or level which is known to everyone including the service users and patients they care for. As a society we place importance on this in and its relation to power (Currie et al., 2009). Nurses and doctors within the sites that I was conducting the study are responsible for the decision-making process relating to restrictive practices and seclusion and the importance of this is reflected in their own codes of professional conduct (NMC, 2015). They are able to decide how and when to administer medication, they are able to decide if someone is put into seclusion and then are responsible for making the decision about someone's suitability to leave the room. Ratcliffe and Kroese (2021) in their synthesis of relevant literature to the topic of the female secure experience hark back to previous studies, already mentioned in this study and its review of the literature, and how power imbalances are key to ensuring we understand the female experience. We have already discussed this in relation to patient involvement within this chapter, but it also potentially impacted on how I was received in the research process by the women and challenged the feminist ideal of breaking down that hierarchy and power imbalance. On reflection it is important to acknowledge your own background, knowledge and values within the research process when considering positionality but also to consider the way in which that background and knowledge might be interpreted by participants themselves within the context of the institution. Power and knowledge are so inextricably linked that the systems of knowledge, in this case constructed by our own professional organisations and hospital institutions, are those that wield the power (Clegg, 1998: 29) and contributes towards the sense of worth of an individual. While I adopted a feminist paradigm, allowing reciprocal questioning, considering the comfort of the woman being interviewed and allowing them to shape

interview questions and content I am also mindful that this approach was also imperative due to the more powerful position that I found myself in within the institutional setting, not just as a researcher but more importantly as a nurse.

#### **5.5 Chapter Summary**

The themes identified within Chapter 4 have been discussed in relation to literature that help to support the meaning of these. The research aimed to identify how these women experienced the reality of seclusion, asking them retrospectively within an interview setting to describe their memories and feelings of the process. Considering the influence of gender and the discourse that surrounds our social interpretations of women detained in secure care I have attempted to link the analysis of the data with concepts including power, autonomy and dignity demonstrating the way in which power balances affect the seclusion experience but also the way in which we gather our data relating to this. Additionally, considering the way in which women may experience seclusion and other restrictive practices does begin to call in to question the way in which legislation and its guidance further supports practices which may not adequately address the imbalance of care associated with either gender, disability or both.

The discussions within this chapter, set out within the framework of the three main identified themes following thematic analysis of the results have highlighted that seclusion for these women is complex.

As seclusion may be construed as having multiple meanings for one individual this demonstrates the sometimes contradictory nature of seclusion and the way in which the experience of the person may be incompatible with the aim of seclusion and the processes that enable it. This is in reference to previous points made through the chapter considering the paradox created by the clinical and needs that the women have in relation to their gender and traumatic histories and that of the Code of Practice (DoH, 2015).

#### **Chapter 6: Conclusions and Recommendations**

#### 6.1 Achieving the aims of the study

This study aimed to find out how women in secure care with a diagnosis of a learning disability experienced seclusion. The study aimed to take a qualitative approach and used Case Study methodology in order to capture the unique experiences and voices of these women. Fifteen women were interviewed and additional data regarding their care and treatment utilised to analyse and then interpret their experiences and their perspective of seclusion.

Embedding a feminist framework and lens within the study allowed me to ascertain the what knowledge we had of these particular groups of women and whether that knowledge had been generated with true acknowledgement of the intersectional and marginalised nature of their circumstances. A review of literature revealed a paucity of meaningful and qualitative data pertaining to women who also had a learning disability across the UK. Studies were few, sometimes outdated or stood alone so that it was important to consider these together in order to form a picture about what seclusion may mean to women with a learning disability in secure care.

Case study methodology with an over-arching feminist framework to guide it allowed for data to be collected by the researcher, enabling prior knowledge, experience and consideration of the relationship within the interview process to be paramount. Care was taken to include the women as far as possible through exploring alternative communication methods if needed, allow them to use the language that suited them best and the environment that they felt most comfortable in meant that trust was established during this part of the research journey. Each woman was able to tell me something of what seclusion meant to them and was given the opportunity in whichever way suited them at the time to tell me about seclusion and the way they felt about it. Results were analysed using thematic analysis (Braun and Clarke, 2021) so that the researcher could really understand and appreciate the full range of the data, down to individual words, expressions and with reflection brought into this process to establish whether my own thoughts and feelings were impacting on interpretation meant that this repeated checking of the data through the thematic analysis phases ensured a more trustworthy and sounder set of results. Using the words of the women verbatim and considering this within the framework of gender and the context of the locked ward meant that interpretation was not simply a comparison with previous studies but the generation of meaning

associated with the often disempowered experience that women have within hospital settings and wider society.

#### **6.2 Limitations and conducting the study**

Commitment and rigour are described as the attentiveness towards the participant and the care taken with the analysis (Yardley, 2000). Research aims looked to capture the voices of these women:

- To find out how women with learning disabilities within secure mental health hospital settings in the United Kingdom viewed their experiences of seclusion. It set out to capture the unique experiences of women with learning disabilities by exploring and analysing their own accounts.
- To inform and contribute to the current policy drive and debate regarding the use of restrictive practices across mental health and learning disability services and include the views of the participants themselves.

It was important that commitment was demonstrated to the women, valuing them as participants within the research process. This was achieved through adoption of the feminist paradigm allowing a reciprocal relationship during the interview process and for them to guide the way in which their interviews were conducted. A Case Study methodological framework ensured that levels of understanding could be checked and that I was more easily and carefully able to interpret their words following interview through interactions with clinical staff who know the women well and their written reports which highlighted areas in which the women needed support around communication and confirmed aspects of the women's accounts.

Rigour was established through the use of a Case Study methodological approach and the choice of Braun and Clarke (2021) thematic analysis model. Ongoing listening, checking and reflection ensured that I was able to transparently reflect the words of the women themselves and show their story through presentation of the results via transcription. Rigour and validity were also addressed through the multi-site approach and triangulating the interview data from Host Site 2 with the interviews from Host Site 1 in addition to the additional sources of data from Host Site 1 inclusive of my own observations and peer debrief with clinical staff at the hospital site. The feminist paradigm which allowed me to focus on issues that may be more relevant to the women, based on their documented clinical presentation but also allowing them the time to tell me their thoughts on being placed into seclusion and to allow them the opportunity to put this into context within the female

ward environment meant that the study was able to generate rich data to support the paucity of literature already discussing the experiences of people with a learning disability.

Limitations of the study included the governance difficulties I encountered when trying to gain access to written information about the women at Host Site 2 in order to corroborate information that the women gave me. Additionally, spending time with the women outside of the interview time itself was on reflection invaluable. This time which I was able to have to some degree at Host Site 1 allowed for an interview more naturally guided or even initiated by the women themselves. It allowed me to observe the women in the ward environment and to reflect on informal interactions with them prior to conducting an interview. Host Site 2 could not allow me this time but did facilitate as well as possible an interview in the ward environment so that women were comfortable to speak with me. Participant numbers were small but each interview provided a unique insight into the experience of seclusion for women with learning disabilities and having fifteen of these yielded some very interesting data. The application across other settings remains something that may be a limitation of this study although conducting the research across two different sites, along with multiple participants within different health sectors in the UK does allow some consideration to be applied to this population.

I have already mentioned transparency in the study. I hope that this has also been evident in the way in which the thesis is structured and written so that the reader can understand the research journey and make sense of the experiences of these women through the way in which I have presented them and reflected on the experiences that I had during my time spent with the women and staff on the wards.

#### **6.3 Main Conclusions and recommendations for practice**

The lens of seclusion was used as a way of capturing experiences of these women through discussion of a process frequently debated and often deplored by those who advocate for the care and treatment of those within mental health services and those who have a learning disability. The voices of women with learning disabilities are not often heard or reflected through literature and it was important that I was able to hear what they had to say about seclusion and to faithfully reflect that back within this thesis. Using the lens of seclusion I was able to establish what seclusion meant to these women and how it reflected the life that they experienced while detained in hospital settings.

The discussions within Chapter 5, set out within the framework of the three main identified themes following thematic analysis of the results have highlighted that seclusion for these women can mean one or more of the following:

- 1. Seclusion as a sensory, calming support
- 2. Seclusion to manage extreme risk
- 3. Seclusion to have some time away from it all linked to point 1
- 4. Seclusion as punishment

As seclusion may be construed as meaning more than one of the above for one individual this demonstrates the sometimes contradictory nature of seclusion and the way in which the experience of the person may be incompatible with the aim of seclusion and the processes that enable it. In Chapter 5 I discussed how the language and the discourse used nationally and even internationally in wider literature can also present difficulties if those implementing seclusion and those subject to it have a differing understanding of its function. Bowers et al. (2012), Happell (2011), Champagne and Stromberg (2004) and Sturmey (2015) are all authors who have contributed to the discussion around the elimination, reduction and the alternative to seclusion and this does not necessarily focus on those who also have a learning disability. Positive Behavioural Support (PBS) approaches continue to be a driving force in the training and support for those working with people with learning disabilities, autism and what we may now term behaviours of concern. Breeze (2021) and McGill et al. (2018) have gone so far as to try to evaluate the effectiveness of positive behavioural support approaches in terms of patient inclusion and even using an RCT approach to their research. My research study can also contribute to this discussion. I do not evaluate positive behavioural support plans and their effectiveness, although all of the women I saw at Host Site 1 certainly had one of these available for me to look at. They included information on likes, dislikes, communication preferences and what staff could do to maximise the person's independence and skills. Positive behaviour support also has at its core a focus on social inclusion, value and independence (LaVigna and Willis, 2005) and my findings have borne this out as something important to the women, demonstrating that the secure environment can reflect a power imbalance which is at odds to the aims of Transforming Care (2012). Being able to demonstrate the impact that the staff have is also supportive to this knowledge and these approaches.

The women often require support to calm. They report that their relationship to staff and the role that staff play in supporting this through demonstration of well-being skills and providing distraction is crucial. The discussion highlighted that this may be a conflict for the qualified nursing staff in particular but the interviews I conducted demonstrate that the therapeutic relationship with familiar

and well-trained staff who understand them is at the heart of preventing seclusion. Additionally, the availability of a space and equipment that can support with calming including sensory equipment (Karen mentions the bubble tube) features prominently in the interviews with the women. This availability and use of sensory, calming space away from others is interlinked with the relationship they have with staff. The women overall find seclusion "horrible" and difficult but do relate that they may require space to calm and that sometimes the seclusion room provides this for them despite the issues surrounding it such as physical restraint, being stripped of clothing and being denied meaningful activity and choice while in there.

During some of the interviews women were eager to share their thoughts on what staff or the hospital might do a little differently. They shared their thoughts on male staff and the role they play in seclusion. They discussed how staff could offer them more comfort where possible, including additional blankets or heating. They also mentioned how dignity played a large role in their experiences of seclusion. The link to risk of self-harm for these women and the seclusion experience was evident but not all of the women understood their own levels of risk in relation to processes such as access to toiletries. However, the women would often report on behalf of each other, specifying that they may not be required to wear rip-proof clothing for example but that others did experience this. Their compassion for each other was evident throughout. This also led some of them to suggest peer debrief and organised support, or as Julie described it, "having a brew", immediately following periods of seclusion.

As highlighted within my discussion chapter, the women are subject to significant regulation as a result of both their legal status within the hospital but also their social status of having a learning disability and associated mental health conditions (Garland-Thomson, 2005). Recently, Goodley (2017) refers to the re-socialisation of impairment which he explored also in his 2001 article (Goodley and Rapley, 2001). This explores the idea that these women could also have moments of resistance, asserting independence and seeking a meaningful life for themselves within the context of the institution they are being detained in. While I did not spend significant amounts of time with the women they were certainly able to assert what they thought should happen to them and sometimes they described moments that to staff and the outsider may appear quite frightening like self-harm and continuing to fight and resist once in seclusion. I also glimpsed moments of real empowerment and close relationships with staff. At Host Site 1 while waiting to interview some of the women I witnessed planning for community outings, charity events, birthday meals and parties. The women spoke to staff about what they wanted to order in terms of clothes and presents for others.

Seclusion is multi-faceted for this group of individuals. That sense of responsibility and coinvolvement of the service user is demonstrated through the use of positive behaviour support
plans, written along with the individual it is designed for. The mention within case reports of words
and phrases such as "appropriate" and "required to calm" shows a sense of expecting the woman to
personally identify and develop skills needed to avoid incidences of seclusion and restraint. Travers
(2013) certainly appears to endorse the concept of empowerment as identified within feminist and
also disability studies (Garland-Thomson, 2010). Travers mentions that services 'maximise the
empowerment process, whilst allowing [the woman] to acknowledge and accept her own
responsibility and accountability for both her behaviours and their consequences' (2013: 81). What I
found though using Case Study methodology is that our written language and discourse currently
does reflect this and the understanding portrayed by staff that featured in my study shows
progression towards this. However, within certain interviews, the women themselves clearly
describe feelings of disempowerment often through the more rigid adherence to legal and
institutional policy that governs situations like seclusion. Equally, that link with staff to the ability to
calm appears significant to the women.

These are stories of coercive measures, societal stigma and for the women, being judged against the expectations of their gender also. This study showed the often-ambivalent nature towards the last resort measure of seclusion, but equally its sometimes perceived less invasive nature meant that they were not then feeling the shame that they would feel at other times when being physically held. Seclusion to some was a preferable alternative. Part of the issue here has been that studies, particularly those that seek to confirm theory with numerical and other empirical data are what drive the continued debate on coercive measures such as seclusion where the majority of data and studies would show its negative effects on an individual or a group of individuals. This study has also done that as evidenced through the bleak descriptions given of seclusion and the pride associated with the success more readily accepted therapeutic measures and subsequent reduction of seclusion incidences. However, the minority are often overlooked, acknowledged but then discarded from the discussion (Emerson, 2016). This is also due in part to the ethical dilemmas that are thrown up when studies focusing on staff experiences highlight the dilemma that staff face between the therapeutic and caring nature of their role and that of the need to make the decision to seclude someone (Muir-Cochrane and Holmes, 2001). Yet this study also shows the important role that the staff play in the seclusion experience for the women. Even that time spent in the room demonstrates the importance of that therapeutic and understanding relationship, knowing that staff are available to talk if needed or just to be there watching them. In these terms the women begin to redefine the meaning of seclusion as we are used to understanding it.

#### Recommendations around the use of seclusion

The recommendations below are conclusions from the findings in the previous chapter and the section outlined above and based on the results and interpretations of this study. However the recommendations are intended as wider and practice-facing so that services can consider how they use seclusion going forward.

#### What the women want

Many of the women made recommendations for themselves and their own experience going forward. They wanted an alternative space to calm that was accessible and better set up for them to use along with staff. However, if for safety they were to be placed in seclusion, they wanted this room to be brighter in colour, for options such as music to be available once they had sufficiently calmed and for staff to talk to them more readily while in the seclusion room. Upon exiting the seclusion room they wanted to know that the other women would be there to welcome them back onto the ward environment. Consideration of the impact of using rip-proof clothing and having male staff involvement is also something that is important to many of these women. Their previous experiences continue to define them and the way that we treat them but when seclusion is used this can be overlooked. All of that knowledge we have around their pasts, histories and clinical presentation can be represented within seclusion plans. I was able to see evidence of this when for some individuals within the study efforts to reduce the incidences of seclusion demonstrated a commitment to the individual, their needs and had been successful.

#### Wider service perspective

Interviews along with the inclusion of written clinical reports, observations and discussions with key clinical staff offered and insight into the way in which seclusion is used at the host sites with women. As we have already highlighted and discussed through this writing up of the study, seclusion continues to be debated in the context of its negative effect on the individual and studies also continue to wonder at the gender difference and the over-reliance on seclusion when alternatives are not available or patients and service users do not fit well into existing services and are therefore more difficult to manage (CQC, 2013). A lack of primary studies also makes it more difficult to share and identify whether there are more evidence-based effective ways of reducing seclusion, inclusive of services for those with learning disabilities (Ching, 2010; Gaskin, McVilly and McGillivary, 2013). However, what my study has shown is that by understanding the difficulties that women experience within the ward environment and the hierarchical and power structures that often govern the processes relating to decision-making and seclusion (DoH, 2015) and moving beyond these through

strong therapeutic bonds and working towards improvement of quality of everyday life alongside staff and peers then this may go some way to reducing the use of these practices. I was told that women were atypical in their use of seclusion while speaking with one of the clinical staff members at Host Site 1 and my study supports this to some degree showing differing levels of self-harm, shame and clinical backgrounds. Our perspectives and tolerance of certain behaviours which may be more prevalent in this population should be examined in order to produce more confident staff that make the decision to seclude when it is absolutely necessary for that individual (Tamminen, 2014).

Table 8 - Recommendations for practice and services

1.	Services should look to offer choice and additional information
	around aspects of seclusion which may not be considered
	automatically as part of the process or within an individual risk
	assessment of plan. This could include aspects relating to
	warmth, use of sanitary and hygiene products, and activity.

This links directly to this study's findings relating to dignity and references made by the women around the denial of certain items of comfort or hygiene due to a perceived generalised risk

associated with their gender.

**2.** Where possible familiar staff should be available to offer

alternative ways of de-escalation. Sensory equipment and rooms tailored to meet the needs of the individuals should be

more readily available and accessible when there is a risk of

heightened anxiety, violence or self-harm. This should be discussed and planned with the individual so that earlier

intervention can happen. The use of an alternative safe space

to the busier ward environment can provide some individuals

with a chance to calm prior to an incident of seclusion but

must be supported by well trained staff. During this study the

women would describe physical sensory items that they have appreciated using inclusive of sensory equipment as well as

making frequent reference to the use and sometimes

inadequate use of a specially designated calming environment.

3.

Services should consider the use of seclusion for women who self-harm. Documenting transparently the reasons for seclusion and the behaviours of women prior to and during incidences of seclusion moving beyond the traditional and required methods of documentation could begin to offer a new perspective that can feed into wider policy discussion. Seclusion processes aimed at reducing risk to self for these women continue to bear out the perception that they are being punished for their behaviour. This is shown in the way in which seclusion relates to issues around dignity, shame and their own sense of worth. Services more widely should begin discussions to look at the use of rip-proof clothing, washing and toileting facilities and how this relates to women's health. A number of women as outlined in the "Findings" chapter believed the primary reason for the use of seclusion related to their proclivity towards self-harm. Equally, this was supported within written documentation relating to seclusion incidences and often citing levels of self-harm as being closely related to the decision to seclude.

4.

Improvement of the understanding of the process of seclusion from a legislation perspective could support empowerment and choice. This could include improving all staff understanding of the relevant aspects of the Code of Practice (2015) and its usability for the women themselves and to improve their level of understanding of the legislation that governs their experiences. What was demonstrated within some of the interviews was that women did not always understand the decision-making process, often drawing their own conclusions as to why seclusion had been used and viewing seclusion sometimes as an alternative to a busy and stressful ward environment.

5.	For services to consider their language within written reports
	about the women, their diagnoses, behaviour and its relation
	to incidences of violent behaviour and seclusion. This study
	demonstrates that some women continue to see seclusion as
	punishment and relate this to threats of violence when
	distressed and the risk they pose to themselves. This is borne
	out by written reports and also the seclusion processes that
	continue to define their experience.
6	

6.

Services should share best practice. With women continuing to be a minority population and then women with a learning disability even more specialised, services are now offering a more gender-sensitive and evidence-based approach to women's care and treatment. Good practice and support should feature as part of a specialised, established network demonstrating an inter-disciplinary approach. Newer and more seminal studies into the female and the female, learning disabled population within secure hospital environments show that researchers draw on each other and are required to scope literature in a way that allows us to find new and deeper meaning within an under-researched and often forgotten area.

#### **6.3.1 Implications for Practice**

Following the outline of the findings and their meaning within the previous chapters and then linking this to practical recommendations is outlined above. However, what are the implications for practice? The study shows that the skills and consistency of staff support is vital for individuals experiencing seclusion. It is therefore important to ensure that this forms part of care planning, risk assessment for seclusion and other associated restrictive practices.

This research can also help to enable service users understand the reasons for seclusion in relation to their own care and to participate in their own planning. Findings can also serve to ensure that de-

escalation and self-management techniques including Dialectical Behaviour Therapy (DBT) are fully supported in order to offer alternatives to and a reduction in such restrictive practices.

The research finds that the descriptions of the seclusion room and their activity are an integral part of the experience of these participants. They comment on how the colour, temperature and availability of privacy affects their sense of punishment, powerlessness and mood. Central to their experience is the lack of activity and long periods of sleeping. This provides information to services in relation to the design and planning of these environments as well as the risk assessment related to individual activity once in the seclusion room and its link to successfully supporting an individual to leave the seclusion room at the earliest opportunity.

The research demonstrates that the institutional use of language by the women does not necessarily reflect their true experience of seclusion but is used as a vehicle to demonstrate more about the power imbalance within and reliance on the hospital setting. While serving as facilitation for some, for others it is potentially a barrier to understanding service user perception.

#### **6.3.2 Implications for Future Research**

The methodological approach taken through the interpretation and use of Case Study methodology has allowed for the individual experience to guide our knowledge and insight into current practices. This research could inform future approaches to enquiring into the lives of people with a learning disability, encouraging participation and an individualised approach that enables us to better understand their experiences through primary qualitative research. Allowing both individual and group cases to be triangulated and considered alongside additional data has meant being able to find deeper meaning and alternative meaning within written evidence about the lives of these women.

This study discovered that seclusion could have a different meaning to those experiencing it from the way in which policy and process has been steered. Seclusion to some, through the use of Case Study approach, was shown at times to be somewhere that women could retreat to and yet to some reinforced an already established power imbalance that they had always accepted and experience on account of their past experiences and at times, their gender. Future research can explore this subject further through involvement of the participant in deconstructing the concepts of restrictive practice and inspire a confidence to involve those in studies whose health may fluctuate over allocated research time.

#### 6.3.4 Mobilising new knowledge

It is important that this research adds to the general paucity of literature within this particular field of learning disability female care and that will inevitably mean that this research can be accessed via relevant databases carrying evidence that is of a good level of impact. It is also desirable that this research can be communicated within academic settings such as conferences with both international and national reach to inform future practice and research. However, it also feels important that the voice of the women in this study is present in dissemination and that this reaches to those directly involved and responsible for their care, treatment and service provision. The use of video logs, social media and professional journals is also a forum for ensuring this less visible group of individuals are at least heard a little more in the future.

#### **6.4 Reflections on the research process**

Reflecting on further difficulties in conducting this study there were two key issues that made gathering rich data more of a challenge. The first of these was the fact that these women had a learning disability and also associated mental health conditions that meant their ability to engage with me would fluctuate. One example of this was during the recruitment phase when women would initially provide consent to be interviewed and then on the day of interview become very fearful and withdraw that consent and refuse to engage. Additionally, in spite of my own knowledge, background and skills as a learning disability nurse it was sometimes difficult to understand the women if they had difficulties with expression and processing and my decision to allow inclusion of clinical staff into the interview process where appropriate or requested was I think the right one. This may limit some of the reliability of the study, however, it was more important to me that these women were able to speak and have their say about seclusion. On reflection, further information prior to interview about their ways of communication, preference and perhaps some of the ways I could have engaged their trust more easily would have been beneficial. Despite this these women were still overall articulate, clear and passionate about telling me about their experiences. It is worth spending that time listening to them, adapting questioning style and allowing them to take their time to answer questions so that data is as rich and meaningful as possible. Allowing the women to support each other also where requested was also invaluable. They supported each other, confirmed information for each other and even though I was mindful to consider the potential for influence I was struck by their care and support of each other during the interview process.

The second issue I faced around the interview process and this study was the environment itself. While I was led as far as possible by the women and interviewed them in a comfortable, safe space I sometimes did not get that choice or opportunity and neither did they. Some interviews were repeatedly interrupted by staff as we were required to sit in a dining room next to a kitchen which caused issues around noise, concentration and arguable confidentiality. Sometimes this was for safety and support for myself, but mostly it was simply because another room was not made available. The ward staff were accommodating where possible but it was not always easy depending on staffing levels and what other activity was happening on the ward at the time to have that time and space allocated. Host Site 1 did manage this a little easier but that may also have been due to the clinical link role of the current Responsible Clinician facilitated for me by the hospital.

There were some women, particularly those within the medium secure unit at Host Site 2 that initially gave consent but then withdrew this on the day I went to interview them. This reflected the need to allow people a certain amount of time to consider whether they really did wish to be involved in the study but also meant that if not feeling like they wanted to participate on that day then consent and even in some cases the ability to consent would inevitably fluctuate. It was important that this was respected and so the process of consent in research with people with a learning disability is vitally important. Not just to get that consent signed but to ensure that all measures are taken for someone to understand that research and to be allowed to express how they feel about participating. Understanding and saying yes often belied a fear about talking and meeting somebody new. At times I was also struck by the power that a researcher can have in this situation. Four of the women asked me if I was there to help them or appeared to believe I at least initially was there to audit and report back to someone in the institution about the care the women received. I realised this put me in a much more powerful position than them in one respect but also a potentially privileged one. I had allowed the women space and time to tell me how they felt about something and to speak about their lives. Some women would even go off at tangents about other hospitals they had been at, other topics other than what I had asked a question about but this was just as important to them and I listened and had the responsibility to report this back in to the Host Sites themselves as well as to record their responses for this thesis.

Taking the time to pilot easy read consent and participant information was useful and allowed the women to feedback on the process and become involved in the research from the very beginning as well as getting to know me a little prior to the data collection phase. It is important that we are inclusive even if emancipatory research is often more difficult to achieve (Goodley, 2017).

#### **6.5 Chapter and thesis conclusion**

I have been honoured to have been given the time to speak to the women recruited in my study and ask them about their experiences of seclusion. I intend for their voices to be added to the ongoing discussion around the use of restrictive practices whether in hospital or in the community. I am aiming for this work to be influential with regard to how services might develop to properly accommodate women whose violence has been interpreted often within an ill-fitting seclusion policy framework. Taking time to listen repeatedly and carefully to their words, being subtle and patient in interview and to consider this within the context of current discussion around the use of seclusion and care provision of people with learning disabilities within hospital settings I found that they had some important things to tell me. Thank you to all of them and I wish them all the best for their futures.

## **Appendix 1** - Consent form for PhD Research

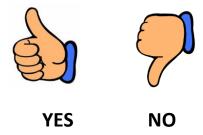
**Short Title of Study**: "Exploring the lives of women with learning disabilities and their experiences of seclusion"

**Researcher**: Helen Goulding, PhD student, Birmingham City University (Tel: 0121 331 7194)

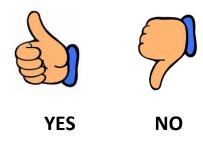
Name of Partici	pant:
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### Please read this form carefully and circle either YES or NO

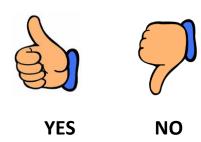
I understand what this study is about



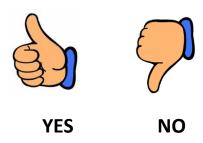
I am happy for you to ask me some questions



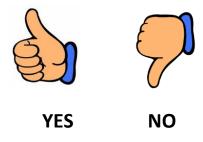
## I am happy if you record us when we are talking



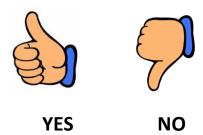
## I understand I can stop if I want to



I understand that you might write about me



I understand that you won't tell anyone what my name is



I understand that you might ask staff a little bit about me. I might ask them what happens when you go into the seclusion room





I understand that you might read a little bit about me from my care notes so that you understand more about me.





I agree to take part in this study







NC

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

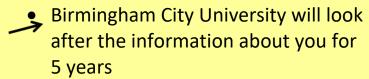
# Appendix 2 - General Data Protection Regulation (GDPR) Information Sheet

# Exploring the lives of women with learning disabilities and their experiences of seclusion



A new law means that Birmingham City University needs to look after information about you for this study.

What does this mean?



 The University will destroy the information after 5 years so no one can see it. This is what the new law says we have to do.

### What if I want to leave the study?



If you want to leave the study then the University will keep your information for 5 years but will only use this if they really need to. The law says we have to keep it for 5 years.

## What information will the University have?

 Birmingham City University will have your name and where you live



 They will know when you had meetings with the researcher

## What will the University do with my information?

- Birmingham City University will use your information to contact you if they need to
- Your information will be locked away in a safe storage area at the University
- The researcher's supervisor can look at your information to check that the researcher is doing the right thing



## Who will see my information?

- The researcher
- The person who is helping the researcher at the University
- You can also see your information if you want to
- No one else will see it



## How can I find out more?

- You can talk to the researcher (Helen)
- You can talk to the Data Protection
   Officer at the University



- The phone number is 0121 331 5288
- The e mail address is informationmanagement@bcu.ac.uk

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## **Appendix 3 – Patient Information Sheet**



- My name is Helen.
- I work at a University
- I want to find out about you



## What do I want to know about?

- I want to know about when you use the seclusion room
- I want to know why you use the seclusion room
- I want to know how you feel when you use the seclusion room

## What will happen?

- I will ask you some questions about the seclusion room
- I will write down what you say



V4 22/08/2019





- I might record what you say
- I might ask staff to tell me

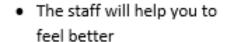
   a little bit about you so I
   can get to know you
   better and understand
   what happens when you
   go into the seclusion
   room
- I might read some information about you from your care notes so I can get to know you better

## Do I have to talk to you?

 NO. You only have to talk to me if you want to.

# What if I start to feel upset?

If you feel upset then I will stop asking you questions





## Will you tell anyone about what I say?

- I want to write about what you say
- I will not tell anyone what your name is
- If you tell me something that is dangerous to you or somebody else then I might have to tell your care team. We might have to stop the interview.



## What if I want to stop?

 If you don't want to talk to me anymore then you don't have to

## Will this help me?

 I think that this will help us to give you better care For further information please contact the researcher:

Helen Goulding, 0121 331 7194

For independent advice please talk to your Responsible Clinician or Independent Mental Health Advocate

#### Sample questions to enable informed consent

#### Questions I might ask staff about you

- · How long you have been here
- Where did you come from
- · Why did you come here
- What do you need help with e.g. feeling sad, feeling angry, self-harm
- How often do you go into the seclusion room
- How long do you usually spend in the seclusion room
- What helps you to calm and come out of the seclusion room
- What medication do you have
- Things that you like to do e.g. going shopping, watching tv, playing music
- How do the staff help you when you are feeling upset or angry

### Information I might read about you in your care notes

- When you first came into hospital
- What diagnosis do you have
- How long you usually spend in the seclusion room

## Appendix 4 – HRA Approval

06 March 2017

Dear Helen

Letter of HRA Approval

Study title: Exploring seclusion and the experiences of women with

learning disabilities within secure forensic services in the

UK.

IRAS project ID: 194689 REC reference: 16/WM/0401

Sponsor Birmingham City University

I am pleased to confirm that <u>HRA Approval</u> has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

## Appendix 5 – Reflective accounts to support analysis

#### Collection of reflective notes showing observations, conversations and triangulation

Writing reflexively for me has meant keeping journal notes detailing immediate and post interview thoughts. These have varied around how I felt, what I saw and the interpretation I had of that and also why I may have thought and felt the way I did. I have also spent time reflecting on the quality of the initial interview data to then guide how further interviews might be conducted, but very much within the context of my own skill as an interviewer or asking for certain environment factors to be adapted with a view to improving the experience for both me and the participant. It is therefore my intention to regularly draw upon these reflective notes and accounts in order to explain analysis and later on to aid my discussion around findings.

Host Site 1 is a secure hospital within the UK which provides medium and low secure services for those with a learning disability, autism and associated mental health conditions. It provides care for those who are subject to section under the Mental Health Act 1983, some of those who have been referred to hospital through the courts and held and treated for example on Section 37/41 (\*\*\*). There are dedicated ward environments for the female service users / patients and for this study I was given access to two wards, A and B. I was permitted to speak with any woman who was willing to answer questions and gave consent on either ward. There were other women who were being held at the time in Long Term Segregation in other areas of the hospital or even in seclusion at the time of interviewing, however I did not speak with them if they were deemed too unwell by the Responsible Clinician for the service and therefore presenting a significant risk to both them and to me if I was to try to speak with them. I did however discuss their situation at times with the clinical staff and I will reflect on some of these discussions at various points in this and the next chapter.

Both of the wards had a seclusion room which was within the ward itself, downstairs. I was permitted to look at the seclusion room while there and also spent a few minutes by myself in the seclusion room on A ward. The seclusion room at the time was dull, not well lit. The window was high up and I couldn't see out of it without standing on something. There was no bed in there at the time although I understood that if women were put into the seclusion room then a mattress would be provided during this time. There was a shower and toilet slightly separate to but part of the seclusion room and the room was painted a sort of pale blue colour. While I made a mental note of how I felt while looking at the room and also remembering some of my own experiences of using seclusion as a nurse previously I was also careful to begin interviews with the women by asking them

what seclusion was like and to describe the room to me. I did not want to make assumptions based on how I had felt being in there or from a staff perspective.

One point I would like to mention now is that at the time of collecting the data at Host Site 1 I was approximately 5 months pregnant. I had been denied access to Host Site 2 during this time and would need to wait for at least another year before I was able to continue data collection at the second site but Host Site 1 had completed a risk assessment and allowed me access to the ward and the women. I noticed while there that I never felt threatened at any point but if the ward became "unsettled" in any way then I would be asked to sit in the staff office. I was accompanied by the RC where appropriate for some interviews. I also mention this fact as it also meant that the women sometimes asked me personal questions relating to my pregnancy. I was not required to complete any additional training in relation to accessing the ward environments prior to data collection at Host Site 1.

Host Site 1 – Ward B. I arrived shortly after the women had had a weekly meeting as a group with their RC who was the consultant psychiatrist to the service. There had perhaps been some miscommunication as the time I had been told to arrive wasn't right as the meeting had in fact been concluded earlier than anticipated and therefore when I sat with the group in their communal lounge area, some of the women were not present as they had left to spend time elsewhere and had therefore disengaged. Of the women still remaining in the lounge area, a couple had actively lain down and were resting and not seemingly wanting to engage in another meeting or conversation. However, some women did eagerly appear to listen to what I had to say when I introduced myself and the study. When I left I did not feel as though this approach had been the best or particularly effective. It was difficult to ascertain their level of understanding of what I was saying and the environment, which was a large space did not make this any easier. However, the fact that some of the women had simply been introduced to me was hopefully beneficial. I also found that when reflecting on the experience later that day at home that I struggled to recall details about the women themselves. For example, I did not know any names, or even what some looked like due to them hiding their faces at times from me.

When I spoke with the women on Ward B, I did things a little differently. I was supported by two members of staff in a small room just off the lounge area within the ward. The women were asked individually if they would like to listen to what I had to say and therefore I had the opportunity to sit in a more intimate environment and speak to the women who came in one to one. This also gave me time to get a feel for their individual needs and to adapt my communication as I saw fit at the time. That is not to say that at that point I had any prior knowledge of any of the women, but my

own experience and listening skills did allow me to engage with the women more positively on this occasion. One woman who did not end up being included in my study came in to meet me but was supported by two members of staff as well as the Responsible Clinician (Consultant Psychiatrist) who was supporting me and the research process. This lady and others when they first met me for interview later on were interacting with me calmly and happily but appeared to lack understanding of the research aims. Although consent and participant information sheets outlined the research study in a way that was designed for the women to understand more easily, this information was either quickly forgotten or deemed unimportant by the women at the first meeting. My interpretation of their lack of understanding but also not wanting to make them feel as though they had made a mistake was based on the interactions and that they seemed to believe I was there to then take information away to report poor practice. They appeared to want the opportunity to outline their dislike of the hospital environment and the treatment they received there. The lady that was being supported by two staff for the reason that she may become distressed and therefore violent kept begging with me to get her out of the hospital. She repeated phrases like "have you come to help me?" and seemed uninterested in the real reason that I was there. When I returned to B ward to begin my interviews, the women I spoke with did remember me whereas I had to introduce myself again on A ward due to the difficulties during the first initial meeting on the ward. The timing and introductions on B ward also meant that I was able to respond more intuitively to each women, for example realise when they were getting a bit fed up of talking to me, needed a break or even becoming a little anxious. It also meant that staff on the ward appeared a little more relaxed about having me in the ward environment. While I stayed within sight of staff at all times when on the ward, I was able to sit comfortably with the women in their lounge area and spend some time engaging in different conversations with them prior to beginning any interviews.

I attempted a number of ways to "recruit" and secure interviews. A schedule showing the days I would be there was posted but women were not keen to change their general daily routines or plans to accommodate my interviews. One interesting feature was that on both wards I began the first interviews by asking for consent and thought that by using the easy read document this would ease the participant into the interview process. However, I soon realised that the women just wanted to begin talking about seclusion experiences and could become distracted easily. It was difficult often to hold their attention for the duration of the consent process and to check understanding even if someone they were familiar with was present. Paradoxically, gaining consent prior to the interviews did not however secure the interviews. While this negated the need to explore consent fully using the form at the start of the meeting with me, the women may still sign they were happy prior to my arrival but then refuse the interview on the day and time allocated. Similarly, some women who had

said they would not be interested in being interviewed then approached me and asked to be interviewed so they offered consent there and then and paperwork was completed straight after the interview had been conducted.

It became clear that simply being present, available and taking some initial visiting time to allow the women to feel comfortable with me was a good way forward. Some visits would be spent largely sitting and drinking tea with the women and then perhaps conducting an interview that same day, or on two occasions, simply arranging to come back and talk to them another time, which they usually did. Some interviews were less well planned. Two women refused to be interviewed formally in a private space but were then quite content to sit in a corner of the lounge with others around and discuss their experiences of seclusion. Some refused the recording device but I felt it important to continue to talk to them and to write as verbatim as possible and others wanted to talk in small groups, maximum of three women involved in the interview.

#### <u>Initial meeting – Host Site 1 Ward B</u>

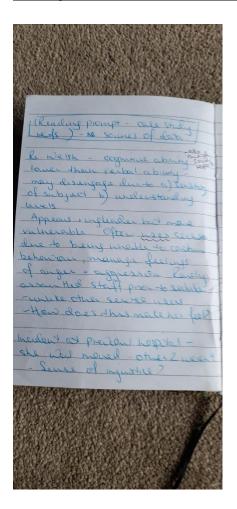
Ward B – This was a difficult time to engage the women. The hope was to meet them as part of a weekly ward meeting in the morning. However, due to some changes in the ward routine I was asked to speak with them immediately following this meeting. It meant a number of women had already begun to disengage from the meeting area. Those who were still there were lying around, buried in their hoodies or their blankets and unwilling to sit up and listen. It was a strange feeling, I knew that the women were likely to behave in this way and by initially adopting that approach that I would previously have done in my professional capacity as a learning disability nurse working in these kinds of services supported my own feelings of inadequacy and uncertainty within this new research context.

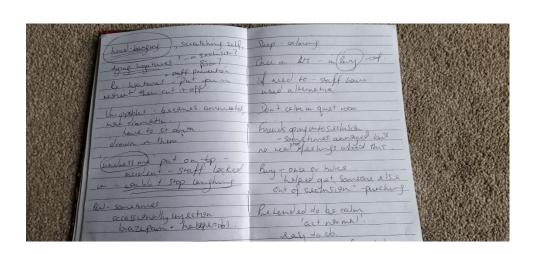
The setting itself did not lend itself to supporting me in my desire to engage the women and for them to really understand what it was I was trying to do. The lounge was large, which made it much harder to engage and reach women who were lying on sofas at the further end of the room. It was also quite dark, without natural light. This situation also meant that it was more difficult for me to gauge whether any of the women had in fact properly heard or understood anything about my study.

#### Reflection on securing interviews at Host Site 1

My original plan was to schedule in times for participants to be interviewed on an individual basis. However, while each potential participant appeared eager and willing when I first met them to introduce my study, when I returned to the ward a couple of weeks later, they were not very forthcoming and most did not want to sit in a room with the tape recorder and be interviewed. While I accepted this, and also acknowledged that this may also be because they did know me well and were aware of the potentially sensitive nature of the topic (\*\*\*), I also felt at a bit of a loss as to how to change this or what I would do if this happened repeatedly. Interestingly during that first visit I decided simply to sit with some of the women in a lounge area and make small talk. I felt that this might help them to relax around me and maybe next time might therefore be different. However, while speaking to them informally, some of them asked me what I was doing and what I wanted to learn about. They then began to speak about their experiences to me, despite the fact I had not asked them directly. It suddenly occurred to me that this in itself was actual data and it would be a shame to lose the opportunity to begin conversations. I therefore asked if they would mind me beginning to record the conversations, which they didn't. I asked if they would like to continue talking in another room, which they didn't, so we remained in the communal living space, and I retrospectively asked if they would formally consent, which they did. Despite my own lack of preparation for this type of situation I was able to elicit around 15 minutes of verbal data between 3 women, who spoke as a group. Interestingly the women also ended the conversation when they felt they had "had enough" and were not shy about telling me that they wished to end the discussion when they felt ready.

#### Meeting some of the women and initial discussions





#### Reflective writing from 30<sup>th</sup> November 2018. Initial interviews at Host Site 2

Had been told that at the beginning of the week, the four women staying on the MSU would be happy to speak to me. I found out they had been spoken to by a male member of staff who they related to well and trusted. This member of staff wasn't present when I went on to the unit four days later. We went on to the ward to be told that it was a little bit "unsettled". At least one of the women was still in bed (11am) and that one lady was quite anxious. We said we would be guided by the staff and they advised that it may not be a very good time to come on and try to conduct interviews. It was unlikely that any of the women would engage.

We then went over to the one of the four LSU wards. On entering it was quite quiet. There weren't many people around. When we went into the lounge / dining area, one of the service users (B) was there with a member of staff. She agreed to be interviewed but there was some attempt to grab at our hands and "ruffle" our hair. She was told by the member of staff in a very light-hearted way that she should sit across the table from us and not to attempt to grab our hair or glasses. I was able to jokingly remove my glasses saying that I needed them to see. The lady was smiling a lot and seemed quite relaxed, however, I did notice that she was shaking quite a lot, with an obvious tremor in both hands. Her speech also seemed a little bit slurred. She was wearing jogging bottoms and a t shirt but the bottoms were quite ill fitting and did not cover her lower back entirely.

The second lady (G) was approached by staff in her bedroom and asked if she would like to speak to us. She came in and appeared quite relaxed and in a good mood. She was eating some food that she said she had had in her bedroom. Again, this lady appeared quite dishevelled and tired. She had poorly dyed hair like (B). She also was visibly shaking, not as though she was cold but as though she had a tremor caused by something. She also spoke in quite a slurred manner. She asked the staff member to retrieve more food from her room which she then proceeded to eat and then quickly lost interest in the interview within a minute of us beginning. We thanked her and told her how well she had done. Despite the lack of actual interview we both thought this had been interesting. While we were just finishing with this lady, the first lady began to cry in the lounge area (interestingly, in this unit there had been no indication or offer of the interview being conducted entirely privately). She mentioned to the staff member that she didn't want to go back into seclusion. The staff member reassured us afterwards when she was showing us out of the ward that it was unlikely we had upset her.

After lunch we went back to the MSU to see if any of the ladies there might be willing to speak to us. We were taken onto the ward and once of the ladies (A) was asked if she wanted to speak to us and

she said yes. She asked to use a side, quiet room and quite happily sat on the settee. We began with the PIS and Consent and then the recording device was mentioned. At that point she decided she wanted to leave and not do the interview. We said that was fine. None of the other ladies on the ward were available to speak to us at that point.

We then went to a second LSU ward. Again we were able to speak to two of the ladies. One lady had been involved in a number of research projects previously and had even spoken at conference events about her involvement in these. She was very happy to speak with us and the interview was easy and enjoyable. Afterwards she offered to help with any conference speaking in the future (she prompted about this). Presumably due to required levels of observation this interview was conducted privately.

On our way out of the lounge area there was a second lady sitting in there and we introduced ourselves and why were on the ward. She had only just come to the hospital from elsewhere but said she had been in seclusion at previous placements. She agreed to speak to us. This interview was with a member of staff present. Doors were open and other service users walked through. This appeared to be due to the levels of observation required and / or the lack of staff available to try to make this interview more private.

#### Some general thoughts

There is a difference in governance and my own access to the service and to the ladies. Previous data collection had allowed me to spend informal time on the ward (sitting, chatting etc) and then approach the interview in my own time. This also meant that interviews differed in their approach between women. This approach (being escorted on, introduced from a distance and only there for the duration of the interview) meant that all had a similar feel in how they were conducted and may have affected whether women were happy to talk or not at that time?

The clinical presentation of the women and the different wards they were on.

The possible impact of staff present or not, shortage of staff on that day, being supported by someone from the research department

## Appendix 6 – My PhD Journey

My journey began in 2015

I was cool, excited and definitely keen.

I wanted to know what some women thought

When locked in seclusion as a last resort.

Learning disabled and needing mental health care,

Stories from these women were extremely rare.

Locked in a ward, abuse as part of their history

But what they really experienced still remains a mystery

The literature thin, no great range

I hoped that my study could make a small change.

I wanted to meet them and hear their words

I wanted to write so that they could be heard.

I read and I read, confused but still keen

What the hell did ontology and epistemology mean?

I knew that I wanted to challenge old trends

So settled on Case Study through a feminist lens

By 2016 I had three hospitals of choice

Yet still hadn't figured how best to give these women their voice

I sailed through ethics, chose two sites carefully

I had a family, full time job, I couldn't travel to three

In 2017 consent paperwork ready and filed
I was told I would soon expect my third child
One site said that's fine, you're ready lets go
The other said too risky, can't come in and no

I met the first group in summer that year

Determined to stay true to my research, remain sincere

Some women were scared, wondered if I was a threat

And some of what they told me I will never forget

The seclusion room's cold, its blue and it smelled

I don't like to be stripped put on the floor and held.

But they also spoke of kindness from staff that they knew

Or the feeling of shame so they hid and withdrew

The end of the year I gave birth to my boy

PhD would have to wait, this was my moment of joy

The following year I returned tired but as calm as can be

I was determined to manage my time carefully

But I don't seem to do anything by half

My next decision made a few people laugh

A new course leader required for the largest nursing degree

Why not I thought, how hard can it be?

Turns out pretty hard, took up all of my time

Fitting study leave in sometimes felt like a crime

But I kept on going, completed the second round

Now I was ready to see what I'd found

So I'm coding my data and writing up too

At times I don't feel I achieved what I set out to do

But then I hear the women speak and I know I'll keep going

Trying to make that change, that new way of knowing

Snatching moments of time amid the chaos and noise
I didn't plan this and being mum to three boys
I have lots of thoughts and loads of ideas
But getting this finished, my biggest of fears

So now its 2020 and I'm still going strong

Its five years and counting, that feels so wrong

A PhD might have kudos, it might open doors

But more importantly it's a journey, its awesome and its yours.

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