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# Doxa Disability and Discrimination

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## Abstract

*This research considers the hypothesis that eugenic ideology still influences social work practice in contemporary Britain. Exploring the issues through a feminist perspective by utilizing a narrative approach with individuals with learning disabilities. For many people with learning disabilities access to 'Human Rights' is rather elusive and this work seeks to examine this through the lens of eugenic ideology and a Bourdieusian approach to social work. The purpose being to ascertain if eugenic ideology is still present, if only through the Bourdieusian concept of "doxa", if so how does this affect the life choices and human rights of the people in the research.*

*Based on the 'lived experiences' of a number of individuals with learning disabilities, all of whom were members of a self-advocacy group in England. All participants had previously been involved as service users in the selection of Social Work students for a London university and were contributors to the programme in this capacity over a period of several years. Involvement of participants in the research with the self-advocacy group was by open invitation to the group members, and individual 'life stories' were documented through recorded interviews by the researcher over a period of several months.*

*Utilizing a narrative approach to the life stories from a feminist perspective the experiences were examined against the historical backdrop of eugenics, articles of the Human Rights Act and Bourdieu's theory of practice. The findings show oppression, inequality and a lack of 'Human Rights' experienced by the participants, this against a policy background of 'Valuing People' and 'Personalisation' which both set out to promote strategies of social inclusion and real opportunities for people with learning disabilities.*

*The 'caring' professions including social work are implicated in the continuing and ongoing oppression and symbolic violence of people with learning disabilities. Whilst the terminology of 'eugenics' is no longer an acceptable topic of conversation, the impact of the ideology continues to permeate the 'collective unconsciousness' (doxa) of many including those who are involved in the decision making processes of individuals identified as learning disabled. The implications for practice is that awareness of the pernicious effects of the eugenic movement need to be taught as part of the history of social work and included in the curriculum, if we are to avoid repeating the horrors of the history of the eugenic movement.*

*By utilizing Bourdieu's concepts of habitus, capital and field, together with doxa and hysteresis it is possible to arrive at a new model of Social Work practice to address discrimination and to promote anti oppressive practice. The "Hysteresis Wheel", is a model developed as a result of this research.*

*No activity of man, whether it be the making of a book, the contraction of a muscle, the manufacture of a brick, the expression of an idea, or the writing of work such as this, can be fully understood without a knowledge of the history of that activity insofar as it has been socially determined. For, obviously, any neglect to take into consideration the relations of the social framework can only lead to a defective understanding of such events.*

*(Montagu 1945:62)*

# CHAPTER 1

## INTRODUCTION

### The influence of Habitus

*It is in their present and past positions in the social structures that biological individuals carry with them at all times and in all places...marks of social positions.... (Bourdieu 1977:82)*

In social work as Pierson highlights, history matters, it is our role to “consider the evidence, search for patterns and trends over time and discuss plausible interpretations” (2011:xi). This thesis aspires to do this. Pierson also reminds us that history is a narrative with a particular viewpoint, it is “both a form of truth and matter of opinion” (ibid).

To independently embark on a significant piece of research requires that the researcher has not only a keen interest in the topic chosen but a desire to make use of the learning achieved. Choice of study is undoubtedly influenced by a researcher's preference; their life experiences to date, their position and their interests, these factors shape the view of objectivity. Adopting Cresswell's worldview as an advocacy/ participatory researcher, which entails engagement with a political agenda for change for marginalised individuals (2009), the approach, accepts the view that post positivist assumptions do not fit marginalised individuals. My own life circumstances, experiences and challenges have without doubt led me to undertake this work because it relates to marginalised people. From a personal sense of a marginalised identity I am endeavouring to create a better society for me, and others as a result of this. Recognising and acknowledging what the 'self' brings to research is understood within a feminist perspective and is utilised within this work. The focus of this research notably and perhaps unusually, is the impact of eugenic ideology, in, and on social work practice and education. I say unusual as for those who have heard of eugenics (and many have not), it is thought to be something that died with Hitler and the Third Reich. If only that was so!

Who we are and how we understand ourselves and our place in the world is shaped by a multitude of factors, many of which we are not cognisant of, yet unwittingly they shape who we are, how we see the world and what we expect from it. As Oktikpidi and Aymer phrase it;

*People are not only shaped by their identity and individual biographies but by the pre-existing narratives that contribute to the ways people see themselves and to the ways in which they relate to other people and to the world around them. (2010:19)*

Whilst the eugenics movement may seem totally at odds within the current value base of social work, it has become apparent to me through working in various social work fields that there needs to be a wider understanding and more encompassing explanation to account for the inequalities, discrimination and oppressions within society. Current theories and models cannot, in my view, adequately address the discrimination, inequality and oppression, experienced by many service users. Why, despite our supposed better understanding of inequality and oppression, do we still have, after so many years of the Welfare State, and social work practitioners with an anti-discriminatory and anti-oppressive focus, a social work service that in the main caters to the same groups and individuals who were assisted by the Poor Laws in the 1800s?

This thesis proposes that the Eugenics movement and its ideological belief in a hierarchy of individual superiority is still present in contemporary society, and that an understanding of this can go some way to explaining why inequality and oppression are continually perpetuated against certain individuals and groups, despite decades of a social work profession working towards equality, social justice and the elimination of oppression with individuals perceived by the eugenicists as "less than". However to challenge the oppression which is generated by eugenic ideology a knowledge of what it is and how it is embedded in society needs to be understood. This is the focus of this thesis.



For a variety of reasons, my own life experience has given me a heightened awareness of the impact of oppression and inequality, and it is a long-standing personal and professional objective to work towards understanding and reducing oppression and inequality within the social work profession. Social work is a profession that defines itself as

*A practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work. Underpinned by theories of social work, social sciences, humanities and indigenous knowledge, social work engages people and structures to address life challenges and enhance wellbeing.*

*(International Federation of Social Work 2014)*

People's motives for entering the social work profession are varied, as the multitude of responses to "Why did you become a social worker?" question posed on the Linked In Social Work Network forum demonstrates (SWN 2015). However, typical of those who enter the profession is the goal of addressing and seeking to ameliorate the challenges faced by the marginalised, the vulnerable and the socially excluded. From my own experience of reviewing the personal statements of social work applicants to UWL between 2007 and 2014 and those responding to the Social Work Network discussion board, most who enter the profession have their own experiences of tragedy, inequality or injustice and are working towards achieving a more socially just society. This is not just for themselves, but also for those who have also experienced the various elements of oppression, injustice and inequality.

It is difficult to precisely indicate which experiences or factors from my own life both personally and professionally have had the greatest influence on my life view, but I am aware of a number of interacting elements, which have contributed to this position. The concern and the desire to undertake this research, of why me, why this subject, and why now, can be clearly traced

back to a Roman Catholic upbringing which gave an experience of being in a minority group, a familial experience of poverty, a personal friendship with someone else regarded as "other" and other adult experiences of injustice and discrimination. I was born the year before Harold Macmillan as Prime Minister told the nation that we "had never had it so good" (Macmillan 1957) and was growing up when Ken Coates was writing the important text for socialist minded individuals, *Poverty the Forgotten Englishman* (1970). Unbeknown to me at the time, I was growing up in the town where this famous individual had been born and I was to become familiar with his work as part of my journey to the social work profession. Also unknown to me at the time, several of the issues of oppression experienced, it will be argued, have a link that relates to eugenic ideology.

These experiences, which have informed my position within a feminist research perspective, range across both personal and professional issues. Being on the receiving end of virtual and vicarious discrimination, being encouraged or cajoled to have invasive ante natal testing to ensure I did not have a second child with special needs, my own social work training, and subsequent Masters level study are all elements that have had an influence on the development of this research. The aim ultimately is to make a valuable and useful contribution to social work education and to achieve a more just and less discriminatory experience for service users and the oppressed.

I have come to realise and acknowledge that the interaction of all the above factors, both personally and professionally, forms the influences on one's life trajectories that ultimately shape the contribution one has to make to the social work world and importantly to the individual service users with whom I have engaged with over the years. As Hesse-Biber notes, "feminist research practitioners pay attention to reflexivity, a process whereby researchers recognize, examine, and understand how their social background, location, and assumptions affect their research practice" (2011:17).

Bourdieu (1977), who I will be drawing on in this thesis, highlights that life experiences and situations become entrenched not only in the fabric of an



individual's make up, but also in their political, social, attitudinal and philosophical approach to life, and likewise the life approach afforded to them. Jenkins (1992) refers to this as the subjectivity /objectivity dichotomy, noting what Bourdieu refers to as "genetic structuralism":

*The attempt to understand how objective, supra-individual social reality (cultural and institutional structures) and the internalized subjective mental worlds of individuals as cultural beings and social actors are inextricably bound up together, each being a contributor to and indeed and an aspect of the other"*

*(Jenkins 1992:19)*

This applies not only to me but also to a multitude of others, whether they are service users, social workers, care assistants, nurses, doctors, or any range of professionals and non-professionals alike. I do not wish to suggest that we are all "condemned" or "entitled" to a particular lifestyle or trajectory for perpetuity, as my own life contradicts this view; nonetheless for some individuals, escaping oppression is extremely problematic and highly unlikely, especially if they carry or embody the stigma of the 'less desirable' from the eugenicist viewpoint. This thesis will explore a range of factors pertaining to the life events of individuals whose life opportunities, experiences, rewards and satisfaction are often and irrevocably predetermined and destined by a limited view of what others would expect of them and the restriction this has placed on their human rights.

For myself as one of the "failed", or so regarded at the age of 11 by the eleven plus selection process, I was acutely aware that my destiny should have been as the factory fodder for the local Staffordshire mills. This view was resoundingly reinforced by the so-called professional career guidance offered to me at 15 years of age. I recall being asked, "So what would you like to do"? My reply of, "I would like to work with children" was greeted by a wry smile and the advice that the nearest factory to my home, manufactured babies' hats!

Was there a connection? Ironically a century or so earlier, these same mills were the first industrial openings and sites of oppression for the female workforce of the day. How was I to know at that tender age that the selection

process by which my life trajectory was supposedly to be mapped out was based on an IQ tool which the eugenics movement had originally sought to distinguish the 'more' from the 'less' able (Omaar 2009).

As an internal UK Celtic migrant I became aware of "difference" from an extremely early age. This difference was not skin colour but Scottish accent, restricted diet and food options, and an obvious dependency on the State, marked out by the 'free school meal recipient' badge. Being impoverished was another aspect of being a less desirable member of society, as I was clearly one of those "too many children from the poor" that those involved with developing the Welfare State (Beveridge 1948) referred to. My different status was plain to see by a lack of appropriate footwear, clothing and PE equipment in the school situation, and at the home address, not attending the local school because of maternal religious beliefs further confirmed difference. My mother a practicing Catholic also experienced oppression from paternal family members for failing to utilise birth control, another issue linked to eugenics (Sanger 1917), being told by my Grandmother she was breeding like a rabbit.

Embedded from the outset either at school or in the local street, where children gathered in response to the instruction to "go out and play" was the fear to speak out openly. I clearly had incorrect pronunciation and usage of various words, which often generated incomprehensible laughter from others and a feeling of isolation and misunderstanding. The feeling of "otherness" predominated as did a strong desire to acquire a dialect and accent which should be considered acceptable, to allow me to "fit in" and belong. Bourdieu recognised the impact of this when he wrote

*We are aware that individuals speak with differing degrees of authority, that words are loaded with unequal weights, depending on who utters them and how they are said.*

*(Bourdieu 1992:1)*

I made considerable effort to acquire the local regional dialect which fortunately or unfortunately, depending on one's values of regional dialect, became a saving grace for me as an individual, in as much as sounding like a

local reduced the amount of bullying, teasing and name calling that I had experienced prior to this acquisition. As Johnes has highlighted, and as I know from experience, regional accent can cause one to be a “victim of sustained attack”; with his reference to Neil Kinnock, he noted the London press called him “a Welsh windbag or bumbling boyo” (2011:33). Ironically this safety mechanism was abandoned speedily as soon as I escaped from the area, now half a century later the tone and inclination in voice has returned to a lilt more in keeping with my original roots. However during those childhood years, it was important to be able to utilise 2 accents, one for outside the home and one for inside. Speaking with a broad Glaswegian accent in the home environment was linked to identity and belonging and was necessary not to offend or alienate oneself from one's family. Bourdieu describes this dissonance, as hysteresis and it will be discussed later in chapter 10.

However this process also meant adopting a false sense of self, and a need to keep newly acquired ‘friends’ away from the home, as their awareness of the difference would also lead to further episodes of intimidation and ridicule, not least because of our impoverished state and the felt difference in lifestyles. Other children it seemed had their clothes washed and ironed rather than worn for several days, or weeks at a time. I lived with the constant fear of being told to “pull up your socks” for the simple reason that they were far too dirty and would have several ring marks on show if this needed to happen. This would generate unkind comments and feelings of shame for factors I had no control over as a child. Local playmates had carpets on their floors, food on their plates at reasonably regular intervals, and an obvious method of heating, for they did not seem to be regularly scavenging in the gardens for pieces of dry wood to use on the fire.

I am acutely aware now that the “close friend” relationship that was established with a girl of Jamaican origin, had a basis primarily because of both of our awareness, even if unwitting, of otherness and difference. This meant that we were both set apart from the rest of the children in the classroom. I considered my position was perhaps easier to overcome than

hers, for example I did not have to experience having my hair touched in the street by complete strangers, as I was considered to be a local, at least by sight, and especially after the acquisition of the aforementioned dialect, but I now realise this is an early absorption of the racism that then and now permeates society.

My friend's pre-determined genetic make-up such as skin colour and hair could not be changed, whereas the tone, inclination of voice and pronunciation of words could be flexible and malleable. I could to some extent collude with the dominant discourse although the shabby dress and obvious poverty were indicators that I was not really one of them. Ironically as a child I considered my Jamaican friend particularly advantaged not just in dress and finances but also in learning terms, for example when it came to spelling tests she could lightly scratch on her arm the more difficult words just before the lesson, this would give her an advantage in the test as they would remain visible for at least the first 10 minutes of the test period. This I knew from our playing of noughts and crosses on the school bus, my own arm would not keep the detail for sufficient time to allow the game to finish.

We were both outsiders although for different reasons. I was a child of an impoverished economic migrant from the industrialised lowlands of Scotland, while she was a foster child of mixed-race parentage from an industrial city; no doubt both of us in unfamiliar territory. She was residing with a white family in a white owner-occupied lower middle-class area, in a comfortable home, with her own bedroom. I was sharing an overcrowded 2-bedroom council property, without a bathroom, with my parents, 2 brothers and an ever-changing number of family relatives who also sought the same economic migrant opportunities away from the high unemployment levels of their original homeland. If she had been the birth child of the family where she lived I think it highly unlikely she would have identified with me, and I would not have learnt or experienced at such an early age the racist society that we have.

Despite our obvious differences, we shared more experiences than one might have expected. To this day I still have the feelings of disquiet of the

discomfort and discrimination I knew she experienced when the class would choose the afternoon reading book of *The Adventures of Little Black Sambo* (Bannerman 1908) the child who wandered the jungle without clothing, without footwear and with just a small umbrella to shade him from the sun. However this story also touched a raw nerve for me being a child with no shoes, clothes or butter! But whilst no mention was made of my clothes or lack of butter, due to school uniforms and free school meals being part of the welfare state at that time, I do recall children unkindly checking to see if my friend had footwear and to comment on why did she need clothes? In any event the story, whether intentionally racist or not, enabled her and me to develop a close bond and I have to say for me a keen awareness of racism to this day.

Ironically, at times I was extremely envious of what appeared to me to be her affluence and her ability to participate in the valued various monetary collections for charitable causes encouraged by the Catholic faith in their schools, though I felt these charitable causes perpetuated discrimination against her. A particular charitable cause that is clearly etched in my brain was that of Father Hudson's Homes a missionary cause which encouraged "pennies for the black babies." At that time if one was able to contribute two shillings and sixpence one allegedly secured the right to name one of these "poor unfortunate babies," a notion which puzzled me and disturbed me even as a child. Whether empathy, which is a valuable attribute in social work (Gerdes & Segal 2009), is nature or nurture it emerged in me as a child. I felt the naming of someone else's child was an infringement on the rights of the child and the parents. I did not expect to experience that situation ever again, although this transpires to be the case for one of the individuals that I interviewed for this thesis. Whether it was my inability, as a child from an impoverished family, to ever secure the two shillings and sixpence or the distaste of naming someone else's child who I would never meet or have responsibility for, I will never know. Suffice to say I never achieved this "honour".

These experiences and events embedded within me awareness, if unnamed,

of injustice, inequality, poverty, difference and oppression. Yet incongruity was the overriding factor. These experiences were set against a backdrop of mixed religious parentage, where Catholic and Protestant parents were considered a "mixed marriage" and undesirable. Perhaps this was one of the earliest inklings that eugenics would be an area for me to study in later life? Such a mixed marriage was clearly frowned upon in much the same way my acquisition of a Jamaican boyfriend later in life was. My own paternal grandmother was a member of a women's organisation allegedly linked to the Free Masons, which we were told as Catholics we were not allowed to join. I am not clear to this day if this is/was true; suffice to say there would often be conversations about events from which my mother and her catholic children were always excluded. Although committed Christians, my father's family, aunts, uncles and cousins found it difficult to attend the various Catholic ceremonies which are part and parcel of the Catholic upbringing, Baptism, First confession, First Communion and Confirmation, with myself and 2 brothers - that was quite a lot of church going and "celebration" that they were reluctant to attend. Although one aunt who considered herself a dressmaker was keen to produce my First Communion outfit, this resembled an austere 1940s wedding dress, whilst other classmates were draped in lace and silk veils as if attending a Royal nuptial. Reflecting on this now it seems amusing. However at the time it came with an immense sense of mortification and feeling of shame that inculcated in me a sense of negativity and difference.

Within my Catholic upbringing and the associated education system that I experienced, it was espoused that all were equal in the eyes of God, a view which I continue to share, regardless of whether there is or isn't a God. Yet I experienced some considerable dissonance when it appeared that this equality only seemed to apply to Catholics; others with no beliefs or different faiths were destined to purgatory. This factor may explain my paternal relatives' reluctance to participate in the various ceremonies. Moreover whilst it was stated that the poor and oppressed needed help, this did not seem to apply to individuals in the immediate locality. Allegedly we were all made in the image and likeness of God himself, as stated in the Catholic Children's



Catechism, which was to be repeated parrot fashion. Moreover from the icons and posters in the school, God was portrayed through his son as a white man with long straight brown hair and a beard, not too dissimilar in appearance to the emerging hippy culture, which was receiving significant rebuke from the Church and others.

For me the contradictions of the Catholic doctrine that were extolled at the time were rather confusing. It was clearly the case that considerable reverence and respect were afforded to and expected for members of the religious orders, such as the priests, Brothers and Sisters who in the main made up the bulk of the teaching staff within the education settings I experienced. So whilst equality, being non-judgmental, respectful and just to others was taught in the religious lessons, being at the bottom of an imposed hierarchy was the real experience. The qualities alluded to in the lessons which included supporting the needy did not appear to extend to the children who were often punished and ostracised for not attending a specific Sunday morning mass or for not contributing to whatever the missionary focus of the week was, let alone the dismissal of discriminatory and offensive comments being allowed to go unchallenged on a daily basis. However, the cruel and demeaning treatment often meted out to the less advantaged and different children within these settings belied the teachings, which were shared in the parables such as the Good Samaritan (Luke 10:25-37). What is particularly ironic is that much of the dissonance that I experienced in those childhood days in regards to values and attitudes has been replicated in the workplace of social work, where there is an espoused commitment to being non-oppressive or discriminatory but the reality belies this.

As life progressed and educational failure at 11 years old was confirmed I appreciated rather quickly that educational and social opportunities would be extremely limited for me, a factor that Bourdieu would also recognise. No academic expectations were held by or placed upon the children of the Secondary Modern school system, a system itself which had been set up in relation to the Butler Education Act of 1944. The intention of this was to allow

the ostensibly more able and gifted to attend the intellectually prestigious Grammar Schools that were also part of that particular reform (Rutherford 2014). Success for the Secondary school child it seems would be measured by having either a job in a local factory or a marriage and children (but not too many) and clearly the choices were anything but plentiful. Having visited one of the local factories as part of the “career guidance” tour days, I had resolved that working within such an environment was never going to be suitable for me.

Unfortunately because of financial imperatives it was necessary for me to find employment of some kind or other, as family income was scarce and at times non-existent. The choice I made was to work as a shop assistant, selling footwear in a local retail outlet in the town. The wages earned in this environment were 50% less than could have been achieved if I had opted to work in one of the local factories. The people who I knew locally could not understand the rationale for opting for such a low paid post. Certainly there was an expressed view that I had ‘ideas above my station’ and I was considered aloof, especially as more financial rewards were on offer elsewhere. However in more recent times I understand from a Myers Briggs personality perspective that I am actually an introvert type and shy. Yet at the time the thought of clocking on and off within specified timeframes, being confined to a factory floor full of dust and fabric pieces, vocal expletives and clattering machinery was something I could not contemplate. The socialisation and banter of this environment that I had witnessed on the work experience visits filled me with dread. To be truthfully honest such an environment was far too scary for me, it seemed preferable to be regarded as a snob and aloof than to face the scrummage and noisy banter of the factory floor. As an exercise in career guidance the tour of the local factory left much to be desired but illuminating it certainly was. So after only a few months of selling shoes, or more accurately stacking shoe boxes, I set out to continue with an education that would possibly lead to the desired objective of working with children, so at the tender age of 15, I travelled 250 miles by coach to the London area to commence a Certificate in Residential Child Care, at a Surrey Technical College.



Although an understanding of Bourdieu's Theory of Practice can adequately explain the experience I encountered, "habitus, capital and field" – "hysteresis and doxa", all concepts that will be drawn on later – these were completely unknown to the 15 year old who arrived in Surrey. After 2 years of study the award in Residential Child Care was achieved, but only just, as the sense of alienation and otherness persisted. The "success route" on offer did not feel as if it was expanding. However the success achieved in the Sociology exam did give me some hope and interest for the future. Unsurprisingly, the available option of early marriage and parenthood appeared more attractive and glamorous than the other options available. From an academic perspective I now understand why this option would have seemed more comfortable and acceptable, but these life experiences have also given me insight to some of the choices that people I have worked with as a social worker have made.

By the age of 18, I was married, had given birth to my first son at age 20 and by the age of 23 was the mother of two young children. I was not aware at the time of what Skeggs subsequently noted was the fear experienced by working class mothers of "never having got it right" (1997:6). Likewise this position has been "categorized as inadequate and inferior" (Skeggs 1997:63). Unsurprisingly I felt I was meeting the expectations the dominant group had of the lifestyle of the lower orders, notably that "working class women, especially (potential) **mothers** are both the problem and the solution to national ills" (Skeggs 1997:48). However, one thing that I did recognise and understood was that my potential was not being achieved, but how this could happen still escaped me.

The sense of injustice and inequality I had experienced to date continued within the hierarchy of the Armed Forces, which through marriage I was now wedded to. My then Grammar school educated husband repeatedly and studiously sought to move up the ranks within the services by continually applying for helicopter pilot training as an Naval Officer, but he was rejected with equal zeal on each occasion, not because of the lack of qualifications

regarding academic ability but because etiquette skills and dress codes were not in keeping with the “officer type”. His inability to effectively utilise a fish knife in the officer’s mess was considered to be sufficient grounds for refusing appropriate pilot training. He was also advised that my refusal to stand for an officer who had chosen to travel on the local bus would be held against him: no less than apartheid by rank.

For someone who is fundamentally an egalitarian committed to social justice, it was extremely difficult to adhere to the expectations of a naval ratings wife. The embedded hierarchical nature of the Armed Forces, with the respect for Queen and country required for this position was extremely alien to a Scottish Catholic of Irish descent with republican views. It appears that my decision to subscribe to the left-wing magazine *Marxism Today* also heralded a nail in the coffin of my husband’s Naval aspirations. However whilst this publication was instrumental in furthering my interest in politics, policy and social justice, its’ decision to advertise S&M underwear on a regular basis caused a cessation of my subscription. At around this time I also became involved in local community support groups, socialist politics and began a journey with feminism, which opened up many new horizons for me, not least in sense of self, but ultimately led to the demise of my marital relationship. However before this occurred I sought out opportunities to further my education in a fulfilling manner, to explore a working life ostensibly committed to tackling inequality, poverty, discrimination and oppression. This journey began at Hatfield Polytechnic in 1982.

On arrival at Hatfield Polytechnic on the induction and enrolment day I was confronted by an administrator who advised me I could not possibly be enrolling on a degree program if I did not have the prerequisite O-levels and A-levels commensurate with such a level of study. Despite having been accepted for the programme I again felt like a fish out of water and undeserving of being in a higher educational institution. Fortunately there were others more mature than myself also enrolling who did not have the required O and A-levels. Despite feelings of inferiority on the day of enrolment and occasional feelings of inadequacy I was successful in completing the

four-year degree in Applied Social Studies and Social Work (CQSW). However it was during my studies and periods of placement that I became fully aware of the potency of injustice and inequality. Bourdieu's work highlights the enduring influence of habitus and capital in the field (Bourdieu 1992) and as stated his theory of practice will be considered in more detail in chapter 5.

As I have alluded to my early life experiences gave me some insight to the racist society which we live in, yet this awareness did not prepare me for the level of discrimination and oppression I encountered whilst training as a social worker. The racist treatment of "offenders" in the Tottenham Magistrates Court will undoubtedly stay with me forever. Following a stop and search of a 17-year-old West Indian, the young man was arrested for illegal possession of a library book. My involvement as a student social worker was to prepare a Social Enquiry Report for the Court, which I did although it seemed totally ludicrous. A week later this same young man was arrested for allegedly carrying an offensive weapon. When I received this information I recall asking, "was it a pencil sharpener?" As I had opted for the Probation option my final placement as a social work student was at Chelmsford prison YOI, more famously known for its fictional inmate Norman Stanley Fletcher, as it was the setting for the TV comedy *Porridge* (BBC). However what went on within this setting was far from amusing; whilst there I came across another young man held in custody for the attempted theft of a handbag of a person unknown! The injustices experienced by both of these young men could not in my view be justified and seemed to stem from a 'belief system' that "Black people" were also morally black (see Fanon 1986). Bourdieu (1977), Young (1990), Thompson (1997) and Mullaly (2007) all offer theoretical models for understanding and explaining the oppression and injustices experienced by these individuals, yet these alone or collectively do not appear to account for how or why this level of oppression originated and remains. I will offer in this thesis a link to the eugenics ideology, which I believe contributes to a fuller understanding of oppression.

Other experiences encountered since qualifying as a social worker which also link to eugenic ideology include the pitiful lack of resources and support offered to offenders, people with mental health problems, the poor, those with learning difficulties or substance misuse. All people considered by the eugenicists as unworthy or undesirables. Often the only services available to such people are “care” (incarceration) in some kind of residential provision miles from anywhere. Although I was aware of the similarities in regards to inequalities and injustices of these diverse individuals, I did not know of any common themes or influences as to why these situations occurred until I came across the eugenics movement as part of an MA course in Sociology/Social Policy some years after qualifying as a social worker.

Having experienced discrimination on grounds of poverty, gender and vicariously race, I was committed to the radical/structural approach to social work (Leonard, 1975 Mullaly, 2003), which perceives many of the difficulties located in the structure of society rather than in the individual. However these alone do not adequately explain the situations and decisions people make. I will show later that Bourdieu's theory of practice, with its ability to link the structural issues with the existential ones, can give a more robust explanation of situations.

Despite having been taught about the origins of the welfare state in social policy and its relevance to social work in my undergraduate degree, at no point had any links been made between the welfare state, its founders or their commitment and adherence to eugenic ideology. Even today little mention, if any, is made in the vast majority of social work degrees about the influence of eugenic thinking on social policy and social work practice, despite the fact that one of the key tenets of eugenic thinking is to reduce the financial cost of the poor to the state.

### The topic of this Thesis

In this thesis I will be setting out a rationale for making a link between eugenic ideology, social work and the perpetuation of oppression, particularly through the theoretical framework of Bourdieu's theory of practice. I contend that the

habitus, capital and field that I have experienced in my own life have given me some significant insights into the manner in which inequality injustice and oppression are perpetuated. However it is not just from my own experience that I wish to consider these factors, but also from the life experiences of others, particularly from those whose voices are often unheard. In doing this, this thesis has adopted a feminist narrative approach to recording the life experiences of individuals with learning disabilities and the impact that oppression and possibly eugenic ideology may have had on their lives. Therefore it will consider if Bourdieu's theory of Practice, can enable us to understand the impact of eugenic thinking on the lives of adults with learning disability and can it assist us to address inequalities and oppression going forward.

In this introductory chapter (1) I have set out my position and the importance of understanding the personal and social context of research, which "feminists have consistently emphasized the importance, of" (Wambui 2013:np).

In the following chapter (2) issues of eugenics and its early Greek and Roman origins are discussed. This chapter then explores the manner in which eugenics acquired a (pseudo) 'scientific' credibility via Social Darwinism. Francis Galton the 'founding father' of eugenics developed a philosophy that was subsequently adopted as a mainstream 'moral' imperative for the (alleged) improvement of the human condition and this developed into a hierarchy for the human race. Ultimately this led to the Holocaust, and to widespread incarceration and sterilisation of those considered 'less than' by the eugenicists and to the earliest state role for 'Social Workers'.

Chapter 3 addresses the historical links of social work to contemporary practice. It explores the history of social work and its relevance in regards to eugenics and considers if the emergence of 'professionalism' is conducive to achieving equality or challenging oppression.

Chapter 4 addresses current practice issues and highlights the benefits of an

understanding of the backdrop of eugenic thinking in the social work field. Moreover it explores and reiterates the need for aspiring social workers to have a knowledge base of the possible origins and links to current oppressive attitudes towards those whom they work with.

In chapter 5 the social context of the perpetuation of inequality and discrimination is explored. This is examined by the utilisation of Bourdieu's 'original conceptual arsenal', which demonstrates how 'doxa' appears to give legitimisation to the marginalisation and oppression of certain groups. In acknowledging the concepts of habitus, capital, and field it becomes clear how certain ideologies and practices become entrenched in individuals lives and social structures. Through Bourdieu's work it is possible to move beyond the dichotomy of existentialism and structuralism towards a more holistic approach to challenging the inequalities embedded in society.

Issues of a feminist narrative approach to research are addressed in chapter 6, and these highlight the importance and benefit of giving 'voice' to those who often go unheard. In the use of narrative it can be seen how 'life stories' are utilised as data and the knowledge of 'bottom up' experiences contribute to an awareness of policy and practice in the social world.

In chapter 7 the process and challenges of gathering the research data is discussed as is the method for engaging with participants. The issue of having to accommodate an ever-changing landscape, within service provision during the research period is also considered as is seeking alternative opportunities to supplement data that was no longer obtainable.

Chapter 8 explores the individual life stories of the research participants and makes links to their lives and similar experiences shared by others. The individual accounts give considerable insight to the life experiences of the participants and the willingness with which they shared their stories. It makes links between the lived experiences shared, the current policy decisions and actions, against the backdrop of persistent oppression towards disabled people.



Chapter 9 explores the links between the daily lives of the research participants with eugenics and Bourdieu's theory of practice. It explores the experiences of oppression through the concept of doxa and brings to the fore the benefit of understanding oppression through Bourdieu's theory of practice.

Chapter 10 considers a way forward for social work practice, utilising the concepts of Bourdieu to re shape and influence a new model of anti oppressive practice. The model incorporates Bourdieu's conceptual arsenal of habitus, capital and field and with his other concepts of doxa and hysteresis encourages a process for understanding and challenging oppressive practices within the social work role.

The Conclusion, chapter 11 summarises the major concepts of this thesis. Notably the impact of eugenics on social work practice, in relation to people with learning disabilities, moreover the insight and benefits Bourdieu's theory of practice can bring to contemporary social work in this field. Concluding with the suggestion of a model based on Bourdieusian theory that can contribute towards the elimination of symbolic violence and oppression.

## CHAPTER 2

### Eugenics

*The 'eugenic' solution is as powerful today as it was in the ancient world of Greece and Rome and has been given a significant impetus by recent developments in biotechnology and genetic medicine (Barnes & Mercer 's (2010:211)*

As Rose states the term 'eugenics' may be considered by some, as "unquestionably unusable" (2007:15) especially since the atrocities of Hitler and the Nazi regime during the period of the Third Reich. However, some are now suggesting that the squeamishness of discussing the more acceptable term 'genetics' has, after a block of fifty years, now been overcome (Rutherford 2014). Many people, if they are familiar with the term 'eugenics' are of the view that eugenics with its past bad press, was finally laid to rest with the horrors of Hitler's extermination camps and the Nazi regime in Germany; "where over 6 million Jews and others were systematically murdered" (Matthews 2009:16).

Who were those 'others'? As this work will show, some of those labelled, as 'others' were a significant number of children and adults with a range of disabilities or incurable illnesses. Whilst these people are considered '*Hitler's Forgotten Victims*' (Evans 2010), what is less well known is that the killing methodology of the despicable gas chambers and starvation halls in the extermination camps of the Nazi regime were tried, tested and refined to 'perfection' initially on disabled children, then later on disabled adults as the Third Reich strived for racial purity (ibid).

As Evans notes, "ridding Germany of children born with disabilities was central to Hitler's vision of the *volkish* (people's) state [and was] a crucial step in his quest for racial purification" (Evans 2010:16). Whilst there is disagreement as to how many children with disabilities were exterminated, during the Nazi regime, it is agreed that the number lies somewhere between 5000 and 30,000. It may come as no surprise therefore that "between January



1940 and August 1941, at least 275,000 Germans with disabilities were [also] exterminated as part of the Nazi regimes Action T4 euthanasia programme” (ibid) as part of the desire to secure the ‘master race’.

As Evans has highlighted, these programs were designed to eliminate all people with disabilities, who according to Nazi ideology “threatened the health and purity of the German race” (2010:15). The elimination of so-called ‘garbage children’ commenced with a decree issued by Hitler in the autumn of 1939. Professionals, for a fee, were to report all children up to the age of three with signs of mental retardation or physical deformity. Henceforth “a panel of medical experts decided which of those children should live or die” (Evans 2010:50). Those who were selected for death were transported to paediatric killing wards where they were given lethal injections or allowed to die slow painful deaths from malnutrition. By 1945, 750,000 people with disabilities had been murdered by the Nazis (Evans 2010:18).

### Eugenics in the UK

Whilst these atrocities may seem unbelievable today the philosophy underpinning Hitler’s action was the rise of what is known as the ‘eugenics movement.’ As Mc Climens and Richardson note, this “was not some esoteric cult movement, [it] attracted interest and approval from many of the great and good of society’ (Grant et al 2010:24). None other than Winston Churchill “was in favour of the confinement, segregation, and sterilisation of a class of person contemporarily described as the ‘feeble-minded’ (Hutchison 2011). Although triumphantly remembered for leading Britain through the Second World War against Hitler and the Nazi regime he is recorded as having written to Asquith in 1910

*That unnatural and increasingly rapid growth of the feeble-minded and insane classes, coupled as it is with steady restriction among all the thrifty, energetic and superior stocks constitutes national and race danger which is impossible to exaggerate. I feel that the source from which the stream of madness is fed should be cut off and sealed before another year has passed.*

*(Cited in Hutchinson 2011)*

Speaking in the House of Commons in 1937 Churchill states

*I do not understand the squeamishness about the use of gas. I am strongly in favour of using poisonous gas against uncivilised tribes.*

*(In Iggulden 2002:np)*

As can be extrapolated from these statements, eugenics was not some fringe activity operating on the margins of society, adopted just by some extreme German Nationalist Socialists. Marie Stopes, famous for her contribution to birth control, is known to have said in 1922 “more children from the fit, less from the unfit, that is the chief issue of birth control” (Kevles 2004:90). The founding father of the Welfare State, Sir William Beveridge was also a keen eugenicist, moreover

*His roots were in a particularly hardline strand of eugenics. He argued in 1909 that those men, who through general defects are unable to fill such a whole place in industry, are to be recognised as “unemployable”. They must become the acknowledged dependents of the State... but with complete and permanent loss of all citizen rights — including not only the franchise but civil freedom and fatherhood.’*

*(Sewell 2009:np)*

So whilst Hitler is rightly castigated for his adherence to eugenic principles, it is clear he was not alone in his desires to ‘improve’ the perceived quality of the population. For many, including those presented as the benevolent founders of the Welfare State, “eugenics was not merely some eccentric hobby or sideline, but central to their social thinking” (ibid).

### Greek origins

The term ‘eugenics’ originates from the Greek word meaning good birth; its earliest practice also has a Greek connection with the Spartan policy of enforced euthanasia for “sick, weak and deformed children” (Barnes & Mercer 2010: 224). Barnett also notes “the idea of manipulating human reproduction to improve the species has been traced back to Plato's Republic (circa 368 BCE) (2004:1742). It is known that a eugenic-type policy was strictly upheld in

the Greek city of Sparta where “the abandonment of deformed and sickly infants was actually a legal requirement” (Garland 1995:14). As an admirer of the eugenic Spartan policy, Hitler throughout the 1920s and 30s utilised the Nazi propaganda machinery to present disabled people as ‘useless eaters’ and individuals with a ‘life unworthy of living’ (Barnes & Mercer 2010:225).

However as we have seen, it was not solely from the earliest Spartan policy that Hitler and the Nazis embraced and implemented eugenic ideology and policy. It was actually far closer to home both geographically and historically where the ‘eugenic’ fervour favoured by the Third Reich was first wholeheartedly adopted. Prior to Hitler developing his strategy for a purified race in Germany, in the UK Leonard Darwin had lobbied the Government for eugenic actions: “he wanted to set up flying squads of scientists, armed with powers of arrest over the poor, to tour the country weeding out the unfit” (Sewell 2009:np). Those considered ‘unfit’ were, in Darwin’s view, suitable to be segregated in special colonies or sterilized. Although remembered for his work against poverty and inequality, Labour MP Will Crooks (MP Poplar 1905 -1921) prior to the First World War is noted to have considered the ‘unfit’ to be “like human vermin who crawl about doing absolutely nothing, except polluting and corrupting everything they touch’ (ibid). Crook suggested they had “no business to be alive” (op cit) and at a Eugenics Society meeting he proposed the use of a ‘lethal chamber’ to solve the problem (Sewell 2009:np).

### Galton and Darwin

“In 1883, Sir Francis Galton, a respected British scholar and cousin of Charles Darwin, first used the term eugenics, meaning “well-born” (knowgenetics.org). It was Galton, Charles Darwin’s cousin, who was the first to adopt and give meaning to the term ‘eugenics’; his eugenic ideology had earlier been promulgated in his 1869 book *Hereditary Genius* (Kelves 2004). Galton’s work on eugenics developed from Darwin’s controversial theoretical publication on the *Origins of Species by Means of Natural Selection* (1859). The theory of evolution as proposed by Darwin “was profound not only for the natural sciences but also for the study of human beings and their social relationships” (Dickens 2000:7).

Darwin's evolutionary theory proposed the concept of natural selection and the survival of the fittest, which Galton transferred to social situations and human beings. Darwin's publication in 1859 commenced with a discussion on the "role of animal and plant breeders in effecting domestic forms of selection" (Dickens 2000:11) then setting out the theory of evolution through natural selection he suggested one general law which would lead to the "advancement of all organic beings, namely multiply, vary, let the strongest live and the weakest die" (Darwin 1859:263). Although considered highly contentious and blasphemous when first published, the theory of evolution and natural selection is now widely accepted.

Although often associated with Darwin, the term "survival of the fittest" was a phrase first coined by the English sociologist and philosopher Herbert Spencer (1864: 444), although it has come to be associated with evolutionary theory and Social Darwinism. Spencer was also a keen supporter of eugenic ideology, which is closely linked to the Darwinian theory of evolution. According to Weikart, eugenics is best understood "as the science of improving human hereditary" (2004:2). Or as Hansen et al suggest, "survival in a eugenics-based milieu is artificially manipulated according to some judgment or consensus on what constitutes fitness" (2008:4). In essence this means rather than leaving the improvement of the human race to chance, eugenics regarded as imperative the scientific and managed application of natural selection to the human race; the ideology behind this being 'the fittest' as predetermined by a particular group would survive and the weak or diseased should not.

Darwin's evolutionary theory had significantly dented the belief in the Judeo - Christian understanding of Creation. As a result, some authors subsequently referred to Galton as the founder of the faith of Eugenics. According to Kelves, he "found in eugenics a scientific substitute for church orthodoxies, a secular faith [and] a defensible religious obligation" (2004:12). This religious obligation was linked to the 'moral' imperative of improving the human race. Galton and other eugenicists were of the view that the improvement of the

human race was a moral obligation; they firmly believed that “if an act contributes to biological decline it is immoral” (Weikart 2004:44).

Galton himself described and defined eugenics as

*The science of improving stock, which is by no means confined to [the] question of judicious mating, but which [...] takes cognisance of all influences that [...] give the more suitable races or strains of blood, a better chance of prevailing speedily over the less suitable. (Galton 1907:17)*

### Eugenicists

As the logo of the 2<sup>nd</sup> International Congress of Eugenics states “Eugenics is the Self Direction of Human Evolution” (knowgenetics.org). The eugenicists considered their concerted actions to be in aid of improving the quality of the human race. The eugenic understanding of being ‘well born’ meant that it was possible and more importantly desirable to utilise the biological theory of hereditary to improve physical, mental and behavioural qualities. The qualities that the eugenicists considered desirable and equated with being ‘well born’ unsurprisingly were those they possessed themselves: as Kelves describes, “passage through schools, universities and professional training” (2004:77). The qualities that they possessed were in their view what constituted human worth and the eugenicists believed such qualities resulted from biological (genetic) inheritance.

Importantly the ideology of eugenics was considered acceptable as it was “advanced in the seemingly neutral language of science” (Kevles 2004:84). To eugenic supporters, those who were in Galton’s terminology ‘less suitable’ were labelled as the feeble-minded, the weak, moral imbeciles, unfit and savages. To the eugenicists these individuals caused grave concern to societal well being, in their view ‘the degenerates,’ another phrase frequently used, were polluting the quality of the species and ultimately leading to what Soloway describes as “race suicide” (1995: xxi).

For the eugenicists two groups were particularly problematic. These were the disabled and non-European races; they viewed these individuals as inferior and or savages and thought their reproduction “contributed to [the] biological deterioration” (Weikart 2004:3) of the human race. As Hiro notes black people were not only the colour of black, but were also morally black “the colour of Satan” (1992:3). Galton ‘knew’ this because his travels to Africa had confirmed the existence of “inferior races” (Kevles 2004:8), an argument that still rumbles on today (Omaar 2009). Moreover in regards to African slaves, these were considered to be “only half human [in fact] an unequivocal race between man and monkey” (Hiro 1992:3). For the eugenicists many societies (especially non-European) consisted of individuals whose levels were set at the level of savages or even animals (Hawkins 1997:76). As an example of this view Churchill (1937) is recorded as stating:

*I do not admit... that a great wrong has been done to the Red Indians of America, or the black people of Australia... by the fact that a stronger race, a higher grade race... has come in and taken its place.*

*(In Iggulden 2002:np)*

In more recent times Frantz Fanon notes “various theories have tried to prove that the Negro is a stage in the slow evolution of monkey into man” (1986:17).

Concerned by *The Rapid Multiplication of the Unfit* (Woodhull 1891), the eugenicists “accepted the fact that if superior people are desired, they must be bred; and if imbeciles, criminals, paupers, and otherwise unfit are undesirable citizens, they must not be bred” (Kelves 2004:85). Scientific progress and evolution would only be achieved if action were taken to eliminate those considered ‘less suitable’. The biologist, eugenicist and political activist Hentschel stated “that which preserves health is moral [and] everything which makes one sick or ugly is sin” (cited in Weikart 2004:43). As Tille the Social Darwinist, who was a key figure in Anglo-German intercultural transfer, and the first to translate Nietzsche into English stated,



*Even the most careful selection of the best can accomplish nothing if it is not linked with a merciless elimination of the worst people.....the worse people the low ones the superfluous ones must be sacrificed*

*(Cited Weikart 2004:45).*

Whilst working as a university lecturer in Glasgow, Tille was of the view that slums were positive for the development of the common good, as they purged society of useless citizens; acts he deemed as ethical, were those that served the improvement of the fittest race or social class (Manz:nd).

Eugenicists were of the view that it would be a false humanity to preserve the degenerate and depraved as this limited space for the healthy and the strong. The healthy and strong and those with intellectual capacity Galton argued, was not linked to men of “puny frames [or] small physical strength” (Kelves 2004:9). The emergence of Darwin’s theory, which implied that human beings were descendants of animals, facilitated the beginning of a new social order, an order that had a hierarchy of individuals and races. The “primary races” were regarded as being positioned differently in the hierarchy. The eugenicists regarded themselves at the apex of this order, the pinnacle of humanity; each race positioned on an evolutionary platform with White Europeans especially of Anglo-Saxon descent at the top, followed by Yellow or Mongolian, then Brown or non-Mongolian and finally at the lowest end of the strata Black or Negro (Bland 2007) <sup>1</sup>. In the new social order human beings were no longer endowed with a special position in the world bestowed by Judeo-Christian Creationism. As descendants of animals at various stages of evolution some were the repository of perfection whilst others were the contaminators of progress. With this new social order came an “altered conception of human nature and the value of human life [which] had far reaching ethical, political and social implications” (Weikart 2004:16) that are still pursued today.

1.(See Gregory’s the Menace of Colour 1925)

### Sterilisation, the way forward

This new prevailing orthodoxy led to a restrictive strategy of reproduction being implemented for the betterment of the human race. The American eugenicist Charles Davenport, who founded the Eugenics Record Office at Cold Spring Harbor in 1910, commented;

*The lowest stratum of society has neither the intelligence nor self-control enough to justify the state to leave its matings in their own hands. On the contrary the defectives and the criminalistics are so far as may be possible, to be segregated under the care of the state during the reproductive period or otherwise forcibly prevented from procreation.*

*(Cited in Duster 2003:135)*

To this end “some eugenicists began advocating euthanasia and infanticide for the disabled” (Weikart 2004:3), an issue which is explored later in this thesis. As part of the propaganda machinery to encourage the elimination of the ‘unfit’ a film advocating the morality of infanticide for ‘defectives’ was produced, with the telling title *The Black Stork* (Pernick 1996). The film originally made in 1916, although several versions were produced, centred on morally justifying the infanticide of disabled baby Bollinger, expressing how important it was that to improve the human race certain steps, although uncomfortable, would really be in the best interests of all. This utilitarian approach suggested that the moral imperative to eliminate defectives was a desirable contribution to society. As Bentham would have noted,

*The object of all legislation must be the “greatest happiness of the greatest number.” He deduced from the principle of utility that, since all punishment involves pain and is therefore evil, it ought only to be used “so far as it promises to exclude some greater evil.”*

*(Bentham 1789)*

This greater evil would of course be seen as the degeneration of the population and particularly of the White European. In America and throughout much of Northern Europe various ‘social hygiene’ initiatives were espoused and implemented. These encompassed institutional segregation and



compulsory sterilisation (Barnes & Mercer 2010:223). The case which set the precedent for widespread sterilisation was the US Supreme Court ruling of *Buck vs. Bell* which in May 1927

*Upheld a Virginia statute that provided for the eugenic sterilization for people considered genetically unfit. The Court's decision, delivered by Oliver Wendell Holmes, Jr., included the infamous phrase "Three generations of imbeciles are enough".*

*(Buck v Bell US Supreme Court 1927)*

In 1920 Hoche and Binding published *Allowing the Destruction of Life Unworthy of Living*. Like Kossmann, the German zoologist, they argued that taking a sentimental view of the value of 'all' human life could only hinder the progress of society (Weikart 2005). The 'betterment' of society required that "whatever [was necessary] to raise the species to an ever higher level of physical and mental perfection was moral" (Weikart 2004:55). This new moral order approach seriously conflicted with the previous prevailing Judeo-Christian ethic of the sanctity of all human life, which 'explicitly forbade, murder, infanticide, abortion and suicide' (Weikart 2004:75). To the contrary, eugenicists were of the view that when

*Medical science indicates, beyond the possibility of a doubt, that it is impossible for them ever to become useful members of society, or when it is obvious that their existence is directly harmful to the species..... Cripples, high-grade cretins, idiots and children with gross deformities should be quickly and painlessly destroyed.... The interests of the species is more important than that of a few individuals useless to society.*

*(Engel 1912 cited in Pernick 1996:23)*

Hoche and Binding (1925), concerned about the potential financial drain on society caused by 'incurable idiots,' felt it was necessary not to succumb to the irrational emotion of pity, particularly when evaluated against the economic demands created and the "terrible heavy burden upon their relatives and society as a whole" (Barnes & Mercer 2010:224). According to Hoche and Binding these 'incurable idiots' were a travesty of the human race and would "occasion disgust in everyone who encounters them" (ibid). As a

result a number of proposals for 'mercy killing' were suggested, as it was considered this might find a use for them, with possible benefits accruing to medical research.

### Eugenics, Policy and the Welfare State

Eugenic ideology considered improvement could be achieved by what is termed positive eugenics and or negative eugenics. Positive eugenics was the encouragement of the more suitable to produce more children. Within the developing UK Welfare State the original intention of the family allowance was such that more affluent and suitable families should receive more financial support than the poor. However it was announced in Parliament in June 1945 (The National Archives 1915-86) the family allowance was to be at a flat rate. Beveridge attending a eugenics meeting in Mansion House that same evening experienced the wrath of members, and needed to reassure them that a differential eugenic rate would be implemented at a later date (Sewell 2009). However considering the differential birth rates between the 'more' and 'less' suitable, it was concluded positive eugenics alone would not achieve the desired results. The alternative required therefore was the resort to negative eugenics, notably the prevention of procreation, or elimination of the less suitable. In Germany alone, between July 1933 and September 1939 "375,000 people were sterilised to prevent the birth of children with a range of hereditary conditions" (Barnes & Mercer 2010:225). America implemented compulsory sterilisation in over 30 states and in Scandinavian countries compulsory sterilisation was also inflicted on women considered to be 'feeble minded'. These policies remained in place until the 1970s; Tilley et al also suggest that whilst,

*Involuntary sterilization is probably no longer a widespread practice in most Western countries, its history sheds light on contemporary practices which can be regarded as constituting a continuation of eugenic practices by other means.*

*(Tilley et al 2012:2)*

### Mental Deficiency Act 1913

In the UK the methodology of preventing procreation and elimination of the less suitable was carried out mainly by the method of incarceration. The

mechanism for achieving this was contained in the 1913 Mental Deficiency Act (MDA), “the eugenic aims of the [A]ct were, in effect, to clear the streets of undesirables” (Mc Climens & Richardson 2010:26). This Act was passed in Parliament with only 2 dissenting MPs, as a result some 40,000 men and women were incarcerated without trial, as they were deemed to fall into various categories such as ‘feeble-minded’ or ‘morally defective’. Many, perceived as less suitable through this Act, remained confined for many decades. As Harris & Roulstone note, the 1913 MDA “legitimise[d] incarceration and justification for segregating those who were deemed to pose a threat to the gene pool” (2011:121). This strategy of mass institutionalisation continued until the late 1960s, alongside ‘voluntary’ sterilisation for women labelled with the new terminology of ‘handicapped’ or ‘mentally subnormal’. As Engwall (2004) argued, “Sterilization would liberate such women, enabling them to live outside of institutions without the danger of pregnancy” (cited Tilley et al 2012:5). Definitions of categories such as handicapped, mentally subnormal were arrived at via IQ tests. These were originally developed to measure cognitive functioning and ability in children. However they became part of the ammunition of the eugenicists to promote their misplaced notion of superiority, and to give ‘scientific’ credibility to the oppressive practices of sterilisation and incarceration (Grant et al 2010, Barnes & Mercer 2010).

As can be extrapolated from previous pages, the views enacted by Hitler and the Nazi regime did not differ significantly from prevailing attitudes of the time. However the extensive pursuit of eugenic ideology and the abject misery caused eventually became abhorrent. Sewell rightly notes, “eugenics was no quickly passing fad” (2009:np), although after Hitler it became unmentionable for decades. Unfortunately, the pernicious effects of eugenics remain.

### Modern Eugenics

In recent times, particularly since the advent of the human genome project, genetic causes of phenomena and inheritance have gained in popularity, with the geneticist Professor Steve Jones suggesting that ‘genetics’ is now perceived as a sexy science (Rutherford 2014). However Professor Jones is also of the view that in many respects we are heading “backwards at speed”

(ibid). As Duster highlights in recent times there has been a significant shift back to a “genetic basis for such disparate phenomena as shyness, rape, mental illness, alcoholism, crime, even social and economic position” (2003:xi). In 1999 a US-based Professor, in a paper presented to the Galton Institute, spoke of the future eugenic potential genetic research could bring stating, “the 21st-century heralds a golden age for eugenics” (Armer 2007:90). According to Duster this has happened “almost imperceptibly” (2003:xi) and he further suggests the line between genetics and eugenics is frequently blurred, leaving Armer to describe this as ‘*eugenetics*’ (2007:90).

In 2003 the former Prime Minister Tony Blair wrote, “Our country has a remarkable scientific tradition” (Dept. of Health 2003:1). Citing Darwin and other eminent scientists, he states they have “greatly increased the understanding of our world and improved the quality of life for everyone” (ibid). More recently in 2013 Dominic Cummings, the former advisor to the Minister for Education Michael Goves, highlighted the link between educational achievement and genetic inheritance, claiming that “70% of a child’s attainment is determined by his or her genes” (Dorling 2015:47). Therefore it is considered that it would be valuable and beneficial to have the genome sequence data, which is now available to predict learning disabilities, to ensure these children are given additional support in the most appropriate environment (Rutherford 2014). Whilst no one would dispute that IQ tests measure something, there is considerable consternation about what that is. Some suggest that it can better predict “whether your mother drives a Volvo” (Omaar 2009:np) than your overall intelligence, Jones and Chan suggest it tests your ability to do IQ tests (Rutherford 2014) and Plomer states it is the best tool to measure underlying ability (ibid). Perhaps more concerning is Professor Richard Lynn’s view that intelligence testing can prove there are inferior and superior beings, stating that Black People have smaller brains, because of black women’s smaller pelvic size so are less intelligent (Omaar 2009).

However it should not be forgotten that Alfred Binet who first developed and administered the IQ test had the intention “to help schoolteachers more

effectively reach students who had difficulty with standard methods of teaching” (Duster 2003:14). However this then resulted in the segregation of black children in American schools (Omaar 2009). So whilst the tests themselves may have been viewed as beneficent, their usage has a far more chequered history. Likewise, as the document *Our Inheritance our Future* (Dept. of Health 2003) states, “advances in genetics will lead to new drugs and novel therapies ... drugs and treatments targeted at the disease-causing fault rather than the control of symptoms” (ibid: 5). This document further adds that the Government will enhance capacity so that it can for example “ensure that by 2004/5 all pregnant women are offered antenatal screening for Down’s syndrome and then counselled by midwives to help them make an informed choice” (Dept. of Health 2003:7).

While this may seem in the best interests of society, as Goble notes, “medical attempts to eradicate disability are not new” (Swain et al 2014:48). This may accurately reflect Jones’ earlier comment that “we are moving backwards at speed” (Rutherford 2014). Malcrida (2013) notes that attitudes informed by former eugenic ideology also persist in current practices in relation to people with disabilities such as segregated supported living, inadequate information regarding reproduction and existing negativity towards individuals with disabilities reproducing. Malcrida terms this “newgenics”. We are aware that developments in genetic technology are fast-moving, not least because of significant public funding being channelled in this direction (Dept. of Health 2003) in their wake they leave a trail of ethical issues, not least because they undoubtedly raise the spectre of the ‘eugenic’ or ‘newgenic’ future. Whilst it may be argued genetic developments are ‘neutral’ it is, as Maynard suggests, “increasingly [that] our genes are understood to hold the key to our identity” (cited in Swain et al 2008:300). Although eugenic zeal was significantly reduced by the horrors of the Holocaust, “the rise of modern genetics has helped to put it back on the agenda” (Goble 2008:28).

Maynard rightly notes, “as we explore cause and effect in genetic inheritance, we are in danger of making the same mistakes about disability as those made when germ theory first took hold” (Swain et al 2008:300). Armer notes too that



James Watson, the DNA pioneer, has called for the eradication of genetic disability" (2007:90). The societal view, which is widespread, is "no one would want to bring into the world someone who was going to suffer the personal tragedy of disability, so being able to identify and eliminate impaired fetuses or even prevent the tragedy before conception must be the right thing to do" (Maynard 2014:301). Goble puts it plainer when he says disability according to societal assumptions is "something that no one in their right mind would choose for themselves or their child" (Swain et al 2008:49). As Solberg has found the view of families and individuals with Downs' syndrome is that "prenatal screening hurts, diminishes and devalues them in various ways" (Kristiansen et al 2010:189). Understandably preventing the birth of a child because of a genetic impairment does not send out a positive message to those who have this condition; on the contrary it may even suggest that such a life is not worth living. As Barnes & Mercer indicate we are now in a position to "select those characteristics that we value and select out those that we do not" (2010:227).

Given the aforementioned it is clear that despite some improvements for the "less suitable" (in Galton's phraseology), "eugenics has not gone away" (Mc Climens & Richardson 2010:29). As McCarthy has stated for women with learning disabilities they inhabit "a world which has both changed hugely and hardly at all" (1999:16). To this end we need to be fully aware of how ingrained attitudes are, especially those that emanate from eugenic ideology. These attitudes permeate the "collective unconscious" (Fanon 1986:188) despite attempts by disabled people and disability organisations to challenge entrenched negativity. As is noted, "ignorance and prejudice remain widespread" (Barnes & Mercer 2010:229). As Dorling in his work *Inequality and the 1%* notes

*It is remarkable - in the early twenty first century, in one of the most advanced and fortunate nations on earth – to have to acknowledge that some people really do believe that some of us are actually of 'better stock' than others. They don't say this out loud, of course. Animal breeding metaphors are hardly acceptable as a way to talk about fellow citizens. But they find other ways of saying the same thing...*

(2015:44)



The eugenicists in earlier times were concerned about the financial burden the less suitable would place on society and their families. As the Fabian eugenicists H.G. Wells noted

*We cannot go on giving you health, freedom, enlargement, limitless wealth, if all our gifts to you are to be swamped by an indiscriminate torrent of progeny,*

*(cited in Sewell 2009:np)*

However as Barnes & Mercer report in contemporary times “the decision to eradicate those considered unworthy of life and/or an economic and social burden to themselves, their families and the state remains largely unchecked” (2010:237). As Evans notes the seemingly altruistic moral philosopher Peter Singer has stated “that killing [...] a chimpanzee is worse than the killing of a gravely defective human” (2010:20) and she rightly concludes that comments such as this “serve as a chilling reminder that the very same ideas and attitudes that led to the Holocaust are still prevalent today” (ibid). Scientist Richard Dawkins gives a perfect example of this type of attitude stating on his twitter account in relation to a question about having a child with Downs syndrome, “Abort it and try again. It would be immoral to bring it into the world if you have the choice (2014). As Hansen et al note

*Most ethicists have simply ignored the potential conflict between bioethics and human rights for disabled people, but a few have acknowledged the conflict and aggressively **argued that the human rights of disabled people should not be protected.** Buchanan and colleagues, for example, argue that disability is unlike sex, race, or other forms of diversity protected by human rights policy, and disabled people should not be protected from discriminatory treatment. **They argue that the eugenic policies of the past were not inherently wrong,** but rather that they were wrongly applied because of the inadequate knowledge base in the first half of the 20th century. They argue for a new, more finely honed eugenics—a modern application of Darwinism..*

*(2008:3-4)*

It is for these reasons that Social Workers committed to tackling oppression need to be aware and familiar with this history, because “those who cannot

learn from history are doomed to repeat it" (Santayana, cited in Grant et al 2010:29).

## CHAPTER 3

### Social Work, Past and Present.

*The “unconscious” is never anything other than the forgetting of history which history itself produces”*

(Bourdieu 1977:78)

### Social Work History

Humphreys, in her text *Becoming a Social Worker*, has a small paragraph entitled “A Short History of Social Work” in which she states:

*The history of social work in the UK is characterised by its commitment to the most vulnerable people in society and by the competing agendas for social care, social control and social change which come into play when we ask: why do people fall by the wayside and how can we help them?*

(2011:4)

The brevity of this statement and the implications of individual failings that it conveys is surprising yet illuminating, in that the history of social work is so often overlooked, especially given the reality of the origins of social work. Moreover from what will be demonstrated in this chapter the origins of social work can hardly be described as “characterised by [a] commitment to the most vulnerable” (Humphreys 2011:4). Does this commitment mean ensuring the population who are in need of support are withdrawn from society or reduced in number? For this reason it is important in this section to elaborate on the historical links of social work to the issues that are discussed in regards to eugenics, learning disabilities, social work and oppression. As Horner rightly acknowledges “becoming a social worker is a journey of personal and professional discovery, and as in all journeys, it might help to know where we collectively have come from” (2009:11). Unfortunately for too many social workers, the origins of the profession are scantily addressed in the training process and the original Welfare State and its founders are usually portrayed as benevolent supporters of the poor, the needy and the dispossessed. Perhaps this wholly positive reputation is slightly undeserved,

although it is necessary to recognise the changing values which each generation experience.

As Pierson has highlighted “the historical development of social work is an essential but neglected element of our understanding of the profession” (2011:x). He also points out that history is not an unproblematic entity as he recognises it is a “bone of contention” (ibid). As he explains “history is both a form of truth and a matter of opinion” (Pierson 2011:xi). Nonetheless he states it enables us to “make the distinction between the inessential and the indispensable” (2011:x). Schama notes that without the background knowledge of history, our “imagination will be held hostage in the cage of eternal now” (2010:np), a snapshot view of how it is can be strikingly erroneous. Moreover as Schama adds the chronology of history is undoubtedly important, and “we’ve all got things to be ashamed of [and whilst] history is admirably dangerous it is not the soft option” (Rahim 2010:np). Parker, in his text *Away from Home: A History of Child Care*, is also cognisant of the importance of having an awareness of the historical perspective, stating

*Today’s problems, policies and controversies cannot be understood without reference to their historical background. The slate is rarely, if ever wiped clean..... However far reaching change may appear to be, their origins lie in what has gone before. The present is constructed from the past.*

*(Parker 1990:108/109)*

Sheldon and Macdonald note, “contrary to common opinion ...social work did not begin in 1963... this was just the period when the legislature began to take an interest” (2009:3). In fact the history of social work goes back much further where it is intertwined with religious influences, the Poor Laws and the Charity Organisation Society (COS). The COS is regarded as being the first organisation that contemporary social work can recognisably identify with, particularly in relation to casework (Pierson 2011). The COS founded in 1869 had a significant impact on the developing profession of Social Work through the use of advocacy and codification of support methods. As Smith notes

*The Charity Organization Society came into being in large part as a response to the competition and overlap occurring between the various charities and agencies.*

*(Smith M.K. 2002:np)*

Focused on family intervention and an alleged “scientific approach” (ibid) it was the basis for the emerging social work profession in Britain. However, as will be explored many of the tasks now associated with the adult social work role are linked to those set down in the Mental Deficiency Act of 1913. Whilst “there are very few” (Sheldon & Macdonald 2009:7), historical accounts of what we can consider as ‘social work’ emerging in the late 1800s, Jordan states, “whereas there were doctors and lawyers, pharmacists and engineers, in Classical Greece and Rome and throughout the medieval period, social workers did not appear until the 19<sup>th</sup> century” (1997:8).

#### Options for Care

Many of the issues social workers engage with today are not new; Newsome points out they are “firmly rooted in the historical developments of institutions” (1992:155 cited in Horner 2009:7). The juxtaposition of institutions and community care in the emergence of social work activity is also significant. Walmsley (2005) rightly notes that the historical account of support for individuals currently labelled as learning disabled either in or out of institutions and the ‘care’ provided is neither fully or accurately documented, as possible contributors to this history are either missing or may have particular biases. Therefore, how the historical institutional ‘solution’ for so called problem individuals was arrived at, also has differing and contradictory perspectives. Thomson (1998) and Walmsley (2005) both give accounts of the ‘care’ concerns for individuals who would be admitted to institutions. The Royal Commission on the Care and Control of the Feeble Minded (1908) noted that it was “inhumane to place those who could not be responsible for their actions in workhouses and prisons....and care should be provided so long as it is necessary for his [the mental defectives] own good” (cited in Thomson 1998:26). Whilst Thomson (1998) suggests that the developments of segregation and institutionalisation that emerged from the Mental Deficiency

Act of 1913 were influenced by factors other than eugenic zeal; he acknowledges, “mental defectives became defined as the central threat facing the nation” (Thomson 1998:20). Legislation was regarded as necessary for ‘care’ of mental defectives, for their own good, for social order and for the racial health of the nation. The MDA 1913 provided for compulsory and permanent segregation of the ‘feeble minded’ and was regarded as a ‘humanitarian’ measure. Unlike the United States, which had implemented sterilisation legislation, the 1913 MDA did not include this measure. Sterilisation was however proposed in a 1931 Bill, although defeated it was supported by the Eugenics Society, Local Authorities, the medical profession and social workers (Thomson 1998).

In 1908 A.F. Tredgold then considered one of the country’s leading experts in mental deficiency, and also a witness to the Royal Commission of 1908 published the most authoritative text in the field of ‘mental deficiency’.

Until 1952 through multiple editions and latterly with the help of his son, this remained the core text for the training of doctors and nurses, in the UK, interestingly it “promulgated both the view that further propagation by people with learning disabilities should be prevented and that society needed to be protected from their lack of usefulness” (Hall 2008:1006). This may offer us some explanation for the entrenched negative attitudes of the medical profession and others towards people with learning disabilities.

### Historical Influence

Sheldon & Macdonald state that the focus of social workers concern are “the poor, troubled, abused or discriminated against, neglected, frail and elderly, mentally ill, learning disabled, addicted, delinquent, or otherwise socially marginalised up against it citizen” (2009:3). In earlier times (MDA 1913), these groups were considered to fall into 2 main categories, the mental defectives, and the impoverished. Mental defectives was an all encompassing term for most of the groups aforementioned, although the terminology of the day was the feeble minded, the inebriate, lunatic, idiots and cretins, imbeciles, epileptics, moral defectives, criminalistic and socially unfit. The impoverished were those who were or became dependent on the Poor Laws and the



workhouses. Moreover it was considered that the impoverished state of these individuals arose out of weakness of moral character or lack of responsibility (Pierson 2011). So it is within these early understandings of 'charitable support' that the ideas of care, humanitarian approaches, casework, assessments and moral prerogatives emerge.

Our forerunners, the representatives of the COS undertook assessments, made moral judgements about the 'vulnerable' and developed the concept of casework. As a result they are described as what we now understand as social work. The emphasis for the COS 'family visitors' was to assess the 'good ' character of the family as this was considered to be the dominant factor in deciding which kind of support was offered. An example of the importance attributed to individual character by COS visitors is reflected by Helen Bosanquet, a leading figure in the COS who comments:

*There is no fact more constantly and impressively borne in upon the minds of those who have seen many people in their home life, that one and the same income will mean comfort in one home and squalor in another. In the one house we find cleanliness and neatness, healthy children and clean faces, a bright hearth and pictures on the wall..... Next door, where possibly more money is actually earned, there is dirt and discomfort, the remnants of one meal are confused with the next, the children are sickly and unclean, the grate is empty and the coal bill unpaid.*

(1903:102)

The importance of character is a familiar and recurring theme within the visitors of the COS, particularly as it was assumed that individuals "of a higher social and financial status were naturally also morally, spiritually and intellectually superior" (Pierson 2011:20).

Many of those involved in 'assisting' the needy embraced the emerging eugenic ideology that supported the notion of superiority across these qualities. Given a 'scientific credibility' at the time, eugenic ideology exerted significant influence and asserted that the situations and conditions, of individuals that we would consider 'vulnerable' were undoubtedly inherited characteristics (see witness testimonies to the Royal Commission (Radnor

Report) 1908). Therefore it was necessary to ensure for the well being of society and the nations 'mental hygiene' that restrictions and controls were placed upon individuals considered to be mentally defective. As Hall notes "Mental defectives were seen as genetically tainted; they should be both separated from society, and prevented from reproducing" (2008:1006).

Bosanquet and others, including Sydney and Beatrice Webb who were influential in the founding of the Welfare State, also contributed to The Radnor Report (Report of the Royal Commission, 1908). This report influential on the Mental Deficiency Act (MDA) of 1913, saw for the first time social workers "employed in the field to carry out the duties of the local authority" (Pierson 2011:73). Their role was to 'assess' and 'detain' where necessary those who posed a threat to the degeneration of human stock, thereby polluting society.

The MDA of 1913 "distinguished four classes of 'mental defectives' namely idiots, imbeciles, the feeble minded and moral defectives" (Eldergill 1997:70-71). Although the Mental Deficiency Act of 1927 substituted the term 'moral imbecile' for 'moral defective' it is clear that the 'morality' of individuals subject to the legislation is of significant importance. Interestingly, writing in 1997 Eldergill adds that the classification system adopted in 1913 resembles that in use today. This is not altogether surprising, as Reiner & Kaufman in 1969 write:

*Poor housing and blighted neighbour-hoods become the receiving ground for persons who are at the bottom of the economic scale, and who, in the main are in this position because of personality difficulties. They are persons who have little success in work and who have had criminal records or a history of family desertion, illegitimacy, alcoholism and so forth. In other words, many of them have serious character disorders, which have interfered with their success in work, marriage and other aspects of social functioning.*

(1969:170-171)

These comments seem uncomfortably similar to the historical descriptions offered by the eugenicists. As we are aware, unmarried mothers also fell into

the category of 'moral defectives/imbeciles' (1913/1927 terminology) that allowed for them "to be sent to an institution for defectives or placed under guardianship" (Higginbotham 2012:n.p.) and this continued until the enactment of the Mental Health Act of 1959, a 'moral' or 'humanitarian' view depending on ones perspective is still evident in the ongoing 'provision/care' of single mothers today. As Gordon Brown suggested in 2009:

*Teenage single mothers will be placed in shared hostels to be monitored by social workers. ...instead of being given council houses and flats, young mothers will be put in "a network of supervised homes".*

*(Brogan 2009: n.p.)*

We might be forgiven for thinking this was 1909.

### Familiar Concept: Assessment

In the origins of social work and statutory engagement with people with learning and other 'problems' encompassed by the MDA of 1913 and the COS we see some rather familiar concepts. The Oxford English Dictionary defines assessment "in terms of judging or valuing the worth of something" (cited in Parker & Bradley 2010:3). In the context of social work Parker & Bradley suggest that carrying out an assessment is a "skilled activity by someone who is competent to judge between the things of different value. It implies the use of standards against which something can be appraised....important[ly] for social workers it is not the worth of the person that is being assessed but the potential for growth and change" (Parker & Bradley 2010:3).

In contemporary social work, assessment is regarded as key to effective practice, as Watson & West note:

*Assessment is at the heart of all good social work practice. It covers a spectrum of activities, from observation and judgements made within the context of an initial encounter through to more formal and complex frameworks of assessment. Its purpose is to enhance understanding of the service users situation helping workers to identify areas for potential change that will assist the development of a rationale for future intervention.*

(2006:30)

Ironically some of the current tools of assessment in social work practice appear to have their legacy in a eugenic evaluation of families, utilising family inheritance and relationships to identify problematic factors. The use of eco maps and genograms in current assessment processes bear striking similarities to Goddard's earlier work on the fictitiously named Kallikak family, which allegedly demonstrated that defective personalities were inherited,

*Goddard's genealogical research revealed that the union with the feeble-minded tavern girl resulted in generations of "mental defectives" who were plagued by illegitimacy, prostitution, alcoholism, epilepsy, and lechery.*

(Dakwa et al 2001/2n.p)

As Parker & Bradley note "the purpose of an assessment in social work is to acquire and study information about people in their environment to decide upon an identified problem and to plan effective options to resolve that problem" (2010:17). The same principles described above also existed within the context of the original social work tasks in 1913, notably to consider detention of the socially unfit and or to encourage a change in moral character. Given the origins of social work assessments, the view "that [a] good assessment is the cornerstone" (Parker & Bradley 2014:47) of all practice, may not have the benevolent or therapeutic flavour with which it is now regarded.

### Morality & Social Control

Moreover as history has shown us, morality and judgements about that morality have always been intrinsic to the social work process. Banks acknowledges that the task of social work "may also be about controlling people in the interests of social order" (2006:2) and that "questions of ethics, morals and values are an inevitable part of social work" (2006:11). The Quality Assurance Agency for Higher Education is in agreement as they state:

*Social Work is a moral activity that requires practitioners to make and implement difficult decisions about human situations that involve the potential for benefit or harm.... Although social work values have been expressed at different times in a variety of ways.*

*(2000:12)*

Perhaps that is why Jordan has commented, “Moral issues haunt social work” (Jordan 1990:1). The reality for social work is that it has always played an extremely “morally charged” (Banks 2006:21) role in society. The people whom social workers engage with are often considered by society as being undeserving, idle, feckless or deviant, terminology reminiscent of earlier times. The task of the social worker therefore is to protect society from “deviant or morally dangerous people” (Banks 2006:21).

Rather than, as Humphrey describes, social work’s historical roots lying in a commitment to the most vulnerable (2011:4); critiques from oppressed groups have vociferously highlighted that the welfare system reinforces “stereotyping, discrimination and oppression” (Banks 2006:20). Moreover, it is “seen as a repressive instrument of social control through individualising problems” (ibid). Or as Foucault suggests, “social reform” should be reclassified as the history of class repression and is in fact “social control” (Foucault 1967).

### Individual or Social issues

As with the “eugenic” enthusiasm for locating problems within the individual and their faulty genetic inheritance, a model also focusing on the individual and their inherent flaws is that of psychoanalysis. In recent and current social work methodology the influence of the psychodynamic approach is still apparent. Moreover its historical basis in psychoanalytical ideology remains part of social work practice (Sheldon & Macdonald 2009). In 2011 Humphrey writes,

*These traditions focus upon the inner world of the psyche, i.e. emotions, memories and internal representations of our relationships with significant others. The inner world of the psyche includes unconscious phenomena, which may be so traumatic*

*that they have been split off from consciousness. Therapy seeks to bring some of this to consciousness in order to heal the splits and to make people whole again.*

(2011:105)

Pierson (2011) suggests that following the First World War there was a move away from the COS 'casework' approach of morality and character flaws as explanations of problems, towards the 'scientific' links espoused by Freud. From the "teaching[s] of Freud and his disciples, there was to emerge not only a new way of thinking about people, but an entirely new way of helping them" (Woodroffe 1962:119 – 20). Yelloly highlights, "within this individualist ethos, problems of the social order were given less prominence while psychoanalytic ideas with their re-emphasis on the individual easily took root" (1980:69).

Pierson (2011) also noted that links between the expansion of psychiatric knowledge and so-called 'mental hygiene' brought about a focus on 'individualisation'. Mental hygiene or rather the lack of it and the perceived deterioration of the British race were phenomena of much concern to the eugenicists. As Pierson highlights post 1918, "individualisation became central to social work discourse" (2011:54) a theme which is re-emerging in current practice.

Pierson suggests that the principles of psychoanalysis and individualisation continued to develop throughout the period following the First World War and reached fruition after the Second. However in reality I suggest little had actually changed; whereas previously 'behaviour' problems or issues, dependent on one's perspective, had been labelled as 'character' problems, these were now reframed in terms of 'personality' and judged using the terminology of "feckless, incorrigible [and] deviant; individuals trying to master primitive psychic energies were regarded as reluctant to submit to higher forms of social authority" (Pierson 2011:55). In other words they were really part of the lesser social orders so much despised by the eugenicists. References were now being made to 'the social problem family' (Starkey 2000) again making links to a perceived inheritability of problems and it was



the social worker's role to pass judgement "on the qualities of the individual personality that either adapts or fails to adapt to the social environment" (Pierson 2011:55).

Humphrey reiterates a focus on 'individualisation' in current practice, in her explanations of cognitive and psychodynamic interventions (2011:105) which she refers to as 'practice wisdom' (2011:104) claiming this is "at the heart of becoming a good social worker" (2011:91). In her discussion of utilising different methodologies from psychodynamic perspectives, she claims that whilst stemming from different traditions they share a lot of "common ground" (2011:103). Humphrey adds "cognitive and behavioural approaches are most appropriate when people need to change their assumptions, thoughts or behaviours, but psychodynamic and Gestalt approaches are far better if people need to make sense of trauma or life transitions and express their emotions" (2011:104). Either way it is a change required in the individual rather than recognising that there just might be an issue within the social structures or even the perceptions of causality of those who are offering 'support'.

Whilst Woodroffe suggests that the expanding influence of psychiatry and mental hygiene was a 'deluge' (Pierson 2011:54) on social work practice and interventions, Sheldon & Macdonald describe the influence more akin to a 'drizzle' (2009:22). Nonetheless whichever it was or is, it has retained a firm hold on practice throughout. Although the links from the Mental Deficiency Act 1913 to eugenic ideology have vanished in the mist, I suggest they are still with us and apparent in Dorling's comment in the preceding chapter, moreover they have become what Bourdieu (in chapter 5) describes as doxa. Although there has been considerable debate about the impact psychologically based developments had on casework (Pierson 2011) there are, I would suggest, more similarities between casework and mental hygiene and "individualisation " than most would wish to acknowledge, especially if eugenic thinking is brought back into the equation.

### Social Work & Professionalism

The influence of psychiatry and psychology on social work practice has a lengthy history. Pierson, referring to psychiatric social workers, notes “on the back of their psychological expertise they were intent on establishing themselves as an elite” (2011:60). As part of their view of their importance and professionalism they established The Association of Psychiatric Social Workers in 1930. However others working particularly in casework also believed that they should be regarded as professionals too (Pierson 2011:57). Yet as Richmond noted in 1917,

*With other practitioners - with physicians and lawyers, for example - there was always basis of knowledge held in common. If a neurologist had occasion to confer with the surgeon, each could assume in the other mastery of the elements of a whole group of basic sciences and of the formulated and transmitted experience of his own guild besides. But what common knowledge could social workers assume in like case?*

(1917:5)

As Sheldon and Macdonald note this is still a question that could be asked today (2011:22). Throughout the 1920s and 1930s there were regular requests for social work to be regarded as a profession, and whilst it offered a measure of professional status for some women, all of whom were middle class, the majority of the work undertaken was on a voluntary basis or received little remuneration (Pierson 2011:57-59). Seemingly therefore the professionalization of social work is not a new phenomenon. Professionalism is an elusive concept, with numerous definitions and interpretations. Moreover it is a term that is often used in occupational and professional circles, and it is difficult if not impossible to measure. As Friedson (1994) suggests, professionalism is an essentially contested concept, and added to this Askeland and Payne (2001) consider that Social Work too is an essentially contested concept. Humphrey (2011) and Payne (2005) however are of the view that social work became a recognised profession in the early part of the 20th century. Although social work has been a registered ‘profession’ with the HCPC since 2012 and prior to this the GSCC, I would not totally concur that social work is regarded by all social workers as a profession. Moreover I

would suggest the drive for social workers to be recognised as professionals that began in the early part of the 20<sup>th</sup> century has still not been fully achieved. Whilst Secretary of State for Health (1992-1995), Virginia Bottomley is reported “any streetwise granny can do social work” (Dominelli in Malina & Maslin-Prothero 1998), perhaps a stance that even today many would share. Whatever, the origins of these views, social work and social workers are rarely portrayed in a positive light. Although the term Social Worker is now a protected title in legislation and requires registration with a regulator, (currently HCPC) professionalism can also distance social workers from the people they serve. For many the role of ‘Professional Social Worker’ seems a contradiction in terms. Rather than seeking professional status, a significant number in the workforce took an anti-professional stance and were of the view expressed by Freidson that

*Professions are the passive instruments of capital, the state, or their individual clients. They exercise little or no influence of their own...*

(1994:86)

As Macdonald suggests, if “the professional project is intended to secure for its members economic and social advantage, thus achieving upward social mobility (1995:63), is this not completely at odds with an espoused egalitarian philosophy of a social work ‘profession’ that promotes social change and development, social cohesion, and the empowerment and liberation of people, with principles of social justice and human rights at its core (IFSW 2014). The International Federation of Social Work (IFSW 2001) states that “social work has grown out of humanitarian and democratic ideals, its value base is about respect for the dignity and equality and worth of all people” (cited in Horner 2009:103). Clearly there is some measure of incompatibility between being a ‘professional’ and being a social worker. Nonetheless the drive to attain professional status is encapsulated by Becker et al. in the proposal that

*In our society, among the most desired and admired statuses is to be a member of a profession. Such status is attained not by going into the woods for intense, but brief,*

*ordeals of initiation into adult mysteries, but by a long course of professional instruction and supervised practice*

(1961:14).

Professionalism therefore for many social workers is a double edged sword, for whilst it is critical to have integrity, transparency and accountability the emphasis of equality and social justice which underpin anti discriminatory and anti oppressive practice maybe at odds with a professional identity. Whilst Freidson (1994) suggests professionals are normally afforded greater amounts of prestige, there is little evidence of that within current social work practice. A defining characteristic of professionalism, notably autonomy (Olofsson 2007:2) is also conspicuous by its absence within the requirements of social work (see Professional Capability Framework: BASW). Nonetheless social work does encapsulate a number of characteristics associated with a professional identity. Downie (1990) suggests 6 characteristics that equate with professional status, skills or expertise from a broad knowledge base, a special relationship with those served, beneficence tempered with integrity, fairness, honesty and an ethical duty, recognised and legalised role, and to discharge these duties effectively, be independent of the State. Independence from the State in regards to duties is to say the least problematic. This has led to the suggestion that social workers (and others e.g. teachers & nurses) are only “semi-professions” (Olofsson 2007:2). Striving for recognition as professionals Olofsson argues this is to “increase or defend their salaries, [their] prestige, traditional work tasks, [and or] to fight for new and more highly valued roles” (ibid).

### Radical Social Work

However not all in the social work ‘profession’ have sought as Freidson has highlighted to aspire to these great heights! In fact as Young (1990) has argued professionalism carries with it a status privilege and is therefore an exercise of power over powerlessness which itself is a dimension of oppression. As Bank states,

*The radical social work approach acknowledged social workers' role as agents of social control on behalf of an oppressive state and called on them to raise the consciousness of the people they worked with, to encourage collective action for social change and build alliances with working class and trade union organisations.*

(2006:38)

Pierson notes, "in general professional status was thought to be elitist, distancing practitioners from those they served and with whom they wanted to be in alliance" (2011:131). Cree notes, "during the 1970s and 1980s, social workers drew attention to the 'social control' aspects of social work practice, and argued instead for a social work practice which aligned itself more fully with service users and the trade union movement" (2003:2). As an early social work educator John MacCunn (1911) stated

*The purpose of social work must be the transformation of the compassionate relief of suffering and the righting of wrongs into a settled resolve to emancipate their fellow citizens from the manifold obstructions of vice, disease, poverty, ignorance, thoughtlessness, which in diabolical alliance baffle the forward struggling strivings of the human spirit.*

(MacCunn 1911:43)

Holman has interpreted MacCunn's statement as meaning "the purpose of social work is to emancipate the poor from oppression" (2001:3). This is a perspective later attributed to the "radical, critical tradition in social work" (Horner 2009:24). As Pierson notes,

*Radical social work in its anti-professional standards triggered a wider debate.... While social workers had been trying to achieve professional status for virtually the entire 20th century – a goal, as we have seen, that had largely eluded them – by the 1970s the view that social work was an occupation whose conditions of work would be most effectively defended by trade union membership extended beyond those who were radical leaning.*

(2011:130-131)

The concerns of the radical social work movement were originally located within the oppression of the working class and trade union movement, but

were later to encompass the oppression of black people and women (Corrigan & Leonard 1978). It was then to “ultimately contribute to the development of the umbrella term [known today] as anti oppressive practice” (Horner 2009:96). As Banks highlights,

*While the contributions from feminist and anti-racist theorists are often highly critical of the Marxist inspired radical social work with its preoccupation with class at the expense of other social divisions they can nevertheless be seen to have grown out of and alongside the radical social work movement of the 1970s, and the collections of articles on radical work in the 1980s included substantial contributions from feminist and black perspectives.*

(2006:38)

Douglas and Philpot encapsulate the radical perspective view of the 1970s in the following statement, “if psychiatry was a ‘con’, a means of control, so also was social work practice as casework” (1998:15). Radical social work’s primary objection to casework was that problems were considered rooted in individuals and personal failings, rather than the structural problems of unemployment, poverty and poor housing. As Horner states

*What radical social work really objected to was the tendency of traditional casework towards a process of individualisation... Casework stood accused of failing to see the causes of difficulties as residing outside the individual [and] within the wider social structures*

(2009:97)

It is of interest to note that the significance and legacy of radical social work does not always feature in social work texts, or where it does it is limited, as in Sheldon & Macdonald, which states that “the radical social work movement reached its apogee in the late 1970s, and then as a result of [a number] of factors its influence faded” (2009:29).

However the concerns of the radical social work movement which challenged an existential cause of social problems is, I would suggest, linked to an opposition that problematic issues are eugenic in nature, a perception which



has a sense of miasma. Viewing individuals experiencing a range of difficulties as the real cause of the problem is reminiscent of the eugenicists who located causation in the character and inferiority of those experiencing difficulties. Young (1990) highlights,

*The 19th and early 20th-century scientific and philosophical discourse explicitly proposed and legitimated formal theories of race sex age and national superiority...the methods of science and the attributes of the scientist have...contributed to the formulation of theories of superiority [and] inferiority.*

(Mullaly 2007:259)

Moreover as Young (1990) explains

*The imposition of scientific reason's dichotomy between subject and object on hierarchical relations of race, gender, class and nationality... has deep and abiding consequences for the structuring of privilege and oppression. The privileged groups ....in assuming the position of the scientific subject they become agents of a universal view from nowhere. The oppressed groups on the other hand are locked in their objectified bodies, blind, dumb, and passive. The normalising gaze of science focused on the objectified bodies of women, blacks, Jews, homosexuals, old people, the mad and feeble-minded. From its observations emerged theories of sexual, racial, age and mental or moral superiority.*

(Young 1990:127)

Although it may seem on the surface that the ideologies of natural superiority and group domination do not hold the influence of previous eras, I contend the forms of oppression that were legitimated in eugenic ideology are manifest and continue within current structures and practices (See Dorling 2015:44). Rahim reminds us, "Britain's past is inextricable from the present" (2010: n.p). The influence of eugenics occurs "through the systemic constraints on subordinate groups that take the form of unquestioned norms, behaviours and symbols and in the underlying assumptions of institutional rules" (Mullaly 2007: 261) otherwise known as doxa. Mullaly therefore suggests that these

oppressions are structural issues and that the problems experienced by certain groups do not lie solely in individualisation.

Although much of the radical approach to social work appears to be downplayed within many social work, 'what it is and how to do it' texts (Sheldon & Macdonald 2009, Humphrey 2011, O'Hagan 2007, Horner 2009), it influenced a move towards a more political stance of working towards social change, anti oppressive approaches and contributed to a number of the values now associated with the social work 'profession',

*Such as equality, collectivism, community and social justice.... Social justice, in particular has been stressed in social work.... Social justice is based on the idea of distributing resources in society according to need.... Challenging existing powers structures and oppressive institutions and actions.*

*(Banks 2006:39)*

### From Radical to Structural Social Work

As can be seen from Banks statement, the current values of social work are now entrenched with notions of anti oppressive and anti discriminatory practice. Anti oppressive practice as Mathews & Crawford note,

*Seeks to make an explicit connection between the impoverishment of individual lives and the oppressive social causes... it has contributed to a progressive perspective within contemporary practice, which does not seek to pathologise the individual for their limitations or failings, but prefers a more holistic approach that considers the social, cultural and political context in which the person lives.*

*(2011:66)*

Whilst the Personal Cultural and Structural (PCS) model devised by Thompson (2006) is familiar territory to most social work students, its origins can be seen in the radical movement. Horner (2009) has suggested that working in radical ways has tended to ebb and flow within social work practice. However as Mullaly states, "there is a sense that social workers are seeking to change the social system and not the individuals who receive,

through no fault of their own the negative results of social arrangements” (1993:124). The influence of the radical movement alongside the civil rights movements of the 1960s of Black and disabled people, particularly in the social model of arrangements cannot be underestimated.

*The social model of disability can be seen as a derivative of the Civil Rights movement in 1960s America, which primarily sought the emancipation of black people and other groups of people oppressed by structural factors within society... it was argued that traditional views of disabled people portrayed them as being passive recipients of services and benefits who required ‘special’ schools, workshops, day centres and training centres where they could be cosseted and managed far removed from ‘normal’ society.*

*(Mathews & Crawford 2011:65)*

Recipients of services and benefits, ‘special’ schools and other places where they can be cosseted and managed *far removed* from normal society would surely sound familiar to those who drafted the MDA of 1913. Mullaly (2007) in a similar vein to Humphrey (2011) suggests that the “values of social work are generally considered progressive and humanistic” (Mullaly 2007:64). However Mullaly also concurs, as stated at the outset of this chapter, the approach taken to individuals and the problems they have experienced is often far from progressive or humanistic.

Raising the awareness of oppression and finding a way forward to achieve social change is the focus of structural social work. Oppression presents itself in many forms and in many ways to different oppressed groups and individuals. As Mullaly highlights “members of oppressed groups are defined in ways by the dominant group that often devalue, objectify, and stereotype them as different, deviant or inferior” (2007:276). Although it is impossible to give a simple and singular definition of oppression Young (1990) has developed a set of categories which each oppressed individual or group will experience at least one or more of. These categories are Exploitation, Powerlessness, Marginalization, Cultural Imperialism and Violence.

### Five Categories of Oppression

For Young (1990) *Exploitation* refers to a set of processes whereby members of the dominant group are able to benefit directly or indirectly from the energy or existence of members of the oppressed group. *Powerlessness* is the restrictions of one's capacities, and also refers to a lack of decision-making opportunities, and it generates "exposure to disrespectful treatment because of the status one occupies" (Mullaly 2007:266). Young describes the powerless as "those who do not have power or authority... exercise little creativity or judgement in their work.... and do not command respect" (1990:59). Social workers as 'professionals' can exert considerable influence over individuals less powerful than them, which is something about which an anti oppressive practitioner should always be cognisant. Young believes that the most dangerous form of oppression is *Marginalization*, because it excludes whole swathes of individuals from being contributors and participants in *normal* (as defined by the dominant discourse) activities of society. *Cultural imperialism* is the manner, in which our social institutions reflect the interests and preferences of the dominant groupings, and as a result measure 'others' who are not the same, not just as different but as deviant and inferior (Mullaly 2007). Finally *Violence* is something Mullaly (2007) and Young (1990) state all oppressed individuals and groups experience simply because they belong to an oppressed group. This violence "includes not only physical attack, but harassment, ridicule or intimidation" (Mullaly 2007:268). All of the above are reflected to some degree in the accounts shared by the research group.

As Albert highlights, "the experience of oppressed people is that the living of ones' life is confined and shaped by forces which are not accidental or occasional and hence avoidable, but are systematically related to each other" (1986:19). Moreover as Bulhan (1985), and Fanon (1986) have explained in their work, structural violence experienced by subordinate groups and individuals ultimately leads to a range of negative outcomes for them, whether

it be in housing, social or health care, morbidity, or lack of access to opportunities which are empowering, liberating or life enhancing. Mullaly states it more explicitly,

*Structural inequalities are socially sanctioned forms of physical and psychological violence, which over time will lead to hurtful discrimination and slow, agonising, premature, and unpunished death. The term structural violence, I contend, more accurately reflects the realities of oppressed persons. Structural inequality is a somewhat abstract, technical, bourgeois, and polite term that covers up its violent outcomes. We should call it what it is – socially sanctioned structural violence.*

*(2007: 276)*

Whilst it is acknowledged that there are episodes of systematic violence and intentional oppression meted out to individuals or groups, for example in personal attacks or harassment, it is argued by Foucault, (1997) Mullaly (2007) and Bourdieu (1977) that most acts of oppression are not intentional, but have become entrenched in the structures of society and the behaviours of individuals. They are then carried out unintentionally and unconsciously in our everyday interactions. Mullaly summarising Foucault (1977) states,

*To understand the meaning and practice of oppression Foucault suggests that we go beyond viewing oppression as the conscious and intentional acts of one group against another. Instead, oppression is often found in such areas as education, the production and distribution of goods and services, public administration, the delivery of health and social services, and the like. In other words many people contribute to maintaining and reproducing oppression in carrying out many of their day-to-day activities, yet they do not understand themselves to be agents of oppression.*

*(Mullaly 2007:261)*

The above findings relating to structural violence and oppression make sorry reading for most social work practitioners who view their “social work activity [as] concerned with social problems, that is, with alleviating, eliminating, or preventing social problems and the deleterious effects they have on people” (Mullaly 2007:64).

## CHAPTER 4

### Valuing People

*Friendship, kindness, respect and humanity; It shouldn't be too much to ask.*

*(Quarmby 2013:239)*

“Social work and social care in Britain have a chequered history. They have been devalued, underfunded, neglected, stigmatised and misunderstood (Beresford 2014:2). It is unfortunate that too many professionals including social workers have “viewed disabled people as tragic, deficient and inferior” (Swain et al 2008:134). Whilst an historical view, the telling comments of a social worker in Malacrida’s research is illuminating,

*Improving the living spaces of these inmates would be a waste of funds and energy, [u]se the money for the people where it's going to do the most good. There are a number of them [inmates] that you might as well be talking to a chicken.*

*(2012:288)*

Although as social workers we may espouse that we are acting altruistically and in the best interests of service users, “some disabled people have come to the conclusion that professionals are self interested and are using them to secure a pleasant and lucrative lifestyle for them selves” (Swain et al 2008:136). However disconcerting this may sound, in 2001 “there [were] as many as 83,000 people in the learning disability workforce (33,000 in local councils, 30,000 in the voluntary and independent sectors, 20,000 in the NHS)” (D of H 2001: 15) Whilst I doubt being considered as a benefactor dependent on disabled people or others who are ‘vulnerable’, is the view of the majority of social workers or care workers there is an extremely critical view expressed by Davis;

*It is a well-established form of parasitism resting on bits of biblical dogma such as ‘the poor always ye have with you’ (John xii 8). The updated version of the old Poor Law, which sustains most of today’s Welfare professionals, depends for its’ continuity on such counsels of despair. It’s become; lets face it, a nice little earner.*



(1993:199)

Whilst the above is extremely harsh it is not surprising that professional practice has received some criticism from the disabled people's movement as it is often considered abusive and oppressive. Moreover as Swain et al note "the credibility of professionals working with disabled people will be discredited even further unless their practice changes radically" (2008:136).

Whilst it is acknowledged that provision and policy towards disabled people has changed in recent years, McCarthy notes, "at another level it is also true to say that little has changed" (1999:15). Tony Blair, the former Prime Minister, in his foreword to the Valuing People document a significant policy initiative to improve the lives of people with learning disabilities, notes "almost all encounter prejudice, bullying, insensitive treatment and discrimination at some time in their lives (Blair 2000:1). Blair further adds that, whether unintentional or not, it is "no less hurtful and has a very damaging impact" (ibid) on the individual. This is reflected in the accounts that have been shared in this thesis. As the Executive Summary of Valuing People also acknowledges "We have to change this situation if we are to achieve our goal of a modern society in which everyone is valued" (2001:9). As 'Valuing People' highlights,

*People with learning disabilities are amongst the most vulnerable and socially excluded in our society. Very few have jobs, live in their own homes or have choice over who cares for them. This needs to change: people with learning disabilities must no longer be marginalised or excluded.*

(2001:10)

Whilst these are great sentiments, in 2015, some 14 years after this commitment to improving the quality of lives for people with learning disabilities, much still remains to be done.

Whilst the Valuing People policy was a positive and aspirational strategy, it has been unable to achieve the goals it set out to meet in 2001. The desire to

move people with learning disabilities from long stay hospitals to more “appropriate accommodation in the community by 2004” (DH 2001:6) has not been met, and this remained the case in 2014 (Tregelles 2015). A further deadline regarding appropriate provision was set following the horrific abuse meted out to people with learning disabilities at Winterbourne View (Minchin 2012) with the Government reiterating its intent to de-institutionalize individuals by 2014, however as Tregelles Chief Executive of Mencap notes, not only was the deadline of achieving de-institutionalization missed, more people with learning disabilities are going into long term care than coming out (2015:n.p.). To date more than 3000 people with learning disabilities are incarcerated in unsuitable hospital provision across the UK.

Whilst claiming, that fulfilling lives was the objective of the Valuing People policy, to ensure “people with learning disabilities lead full and purposeful lives in their communities and develop a range of activities including leisure interests, friendships and relationships” (Dept. of Health 2001:17), these aspirations remain a long way off. Moreover the 5-year goal contained within Valuing People, of modernising local council provision, led to a range of anomalies, which included closing a range of predominantly day care provision, replacing this with personal support workers, then austerity cutbacks removing the support.

In 2001 the majority of staff (75%) working with people with learning disabilities were unqualified (2001:8). Although claims were made that workforce training amongst health and social care staff would lead to “a better understanding of the needs of people with learning disabilities” (Dept. of Health 2001:26). The most recent data however does not show a significant improvement, 16% of staff in day care are qualified to NVQ level 2/3 with 4% qualified to NVQ level 4 /4+. In residential settings the figures are 24% qualified to NVQ level 2/3 and 4% at NVQ level 4/4+ (Hussein & Manthorpe 2010). From the data available it is not possible to extrapolate specific client groups, however it is understood the vast majority in these figures are supporting people with learning disabilities (ibid).

Whilst the Government set out in the White Paper for more choice and control for people with learning disabilities it is abundantly clear that aspirations alone do not transform into reality. As *Valuing People* found in 2001

*Many people with learning disabilities have little choice or control in their lives. Recent research shows only 6% of people with learning disabilities having control over whom they lived with and 1% over choice of carer*

*(D of H 2001:9)*

### Valuing People Now

Whilst the aspirations of the Valuing People strategy was to significantly improve the life chances of people with learning disabilities, Valuing People Now set out to focus on outcomes in Health, Housing and Employment. Disappointingly whilst reports from the various Learning Disability Partnership Boards in 2010 suggested 'good' progress in several outcomes they acknowledged there was still more to do. Undoubtedly, as the findings show, only 6 in 100 people with learning disabilities have jobs, much still needs to be done in regards to housing, and in health only 50 % of people have the health checks they are entitled to (Dept. of Health 2010). More concerning is the Government Inquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD) this found premature death a significant factor in their lives. As Heslop notes,

*People with learning disabilities are dying, on average, more than 16 years sooner than anyone else. The cause of their premature death is not, like many in the general population, due to lifestyle-related illnesses. The cause of their premature deaths appears to be because the NHS is not being provided equitably to everyone based on need.*

*(2013:np)*

Given these unacceptable findings it is difficult to decipher how this equates with 'good progress'. The authors of the report (CIPOLD 2013) state "these are shocking findings and must serve as a wake-up call to all of us that action is urgently required" (Learning Disability Today 2013:np).

### Personalisation

As Beresford states “Personalisation is without question the dominating idea and development currently in social work and social care” (2014:1). Whilst it is presented as the breakthrough policy initiative to improve people’s lives, some of its strongest critics are service users themselves and their organisations. Although the term has no robust definition, all political parties have adopted ‘personalisation’ wholesale. Carr describes it as “imprecise, ambiguous and contains...inconsistencies and tensions” (cited in Beresford 2014:27). Moreover Hart suggests the word needs to be abandoned altogether as it has “become redundant, meaningless and indeed toxic, in terms of not meaning what it says” (in Needham & Glasby 2014:113). In a similar vein to eugenic thinking in a previous era it has come to be considered an “article of faith” (ibid) within the Department of Health.

The intention of personalization was to transform the lives of people in receipt of services, “a system of care and support designed with their full involvement and tailored to meet their unique needs” (Beresford 2014:5). The individual budget (IB) a significant part of the personalization agenda would allegedly enable and facilitate individuals to choose what type of provision or support met their specific needs. The Government vision to ‘personalize’ support services has meant a significant number of people with learning disabilities and their carers are now or are likely to be in receipt of personal budgets,

*Government policy states that personalization should be ‘embedded within all local authority services and developments for people with learning disabilities and their family carers, and [be] underpinned by person-centred planning’ (Department of Health 2010).*

*(cited in Hussein & Manthorpe 2010:96)*

Whilst the origins of personal budgets, which stemmed from the disabled peoples movement, Duffy (2014) now considers it to have been hijacked for political ends. Describing it as “Zombie personalization” he states it is “now a mixture of the good, the bad and the ugly” (Duffy 2014:178). Moreover it has become “the means by which cuts have been introduced” (ibid). Sadly the

measures heralded to such fanfare in the best interests of vulnerable people have transpired “to be a dispiriting story of unfulfilled promises, greed and confusion” (Duffy 2014:179). As Duffy a former supporter of ‘In Control’ concludes, what is done in the name of ‘personalization’ is in fact an underlying hostile view of disabled people that is presented as positive whilst simultaneously undermining the rights of disabled people.

This is demonstrated by the constant erosion of services and support, culminating in the axing of the Independent Living Fund (ILF) by the current UK Government in June 2015. A disability campaigner described it thus, “it is like 30 years of campaigning and progress have been stripped away in one go” (O’Hara 2015:10). Burnip of Disabled People against Cuts, states. “The closure of the ILF in England will exacerbate the grave and systematic violation of disabled people’s rights to live independently in the community” (O’Hara 2015:10). As O’ Hara also notes “the ILF has represented much more than vital financial support” (ibid): it has been used to facilitate and enable independence for disabled people many thousands of whom had learning disabilities.

Despite the fact that the right to independent living is enshrined in the principles of the United Nations Convention on the Rights of People with Disabilities (UNCRPD), according to the union Unite the current Government “has shown a complete disregard for disabled people” (Unite 2015:n.p.). O’Hara has described the removal of the ILF as “the most regressive, inexplicable and indefensible actions taken under the austerity programme” (2015:10). As Endean of Unite also states, “the closure of the Independent Living Fund will have a catastrophic impact on disabled people and their right to live independent and fulfilling lives” (2014:np). This has proven to be the case, as Morris presenting the foreword to the evaluation of the impact of the removal of the ILF states, disabled peoples “rights are under sustained attack” (2016:5).

### Is Eugenics Implicated?

Given that attempts to achieve a more enlightened, egalitarian and just

approach to individuals with learning disabilities has been continually thwarted, what are the common themes underlying this ongoing oppression? As *Valuing People* states “Until the 1950s, it was generally accepted that people with learning disabilities could enjoy a better quality of life living with other disabled people in segregated institutions rather than in the community with their families” (D of H 2001:16). Is this really the case, and was it ever? Or was the real reason for the incarceration more informed by the underlying eugenic attitudes that were highly prevalent at the time? Segregation and incarceration had stemmed from the Mental Deficiency Act (MDA) 1913, legislation highly influenced by the prevailing eugenic ideology. As Quarmby highlights, the MDA 1913 “passed into law not least because of the great pressure exerted by eugenicists” (2013: 58) and although Churchill had not secured his desire for compulsory sterilisations to “prevent the stream of madness” (ibid) as the US had done, the MDA 1913 had achieved the next best thing and approved the confinement and incarceration by the State of individuals presumed ‘undesirables’. The irony of the disgust towards the Nazi atrocities is hard to comprehend given the origins of the eugenic ideology, which is very much entrenched in British politics and society. As the Wood Committee Report of 1929 stated, “If we are to prevent the racial disaster of mental deficiency we must deal with the whole subnormal groups” (Gillard 2011:n.p). As history tells us this is exactly what Hitler did. However in 2001 the rationale for the longstanding segregation and incarceration is given a more benevolent and therapeutic description and consequently the real cause of oppression remains an un-discussed topic.

Those involved in the development of the Welfare State, as mentioned previously were also avid supporters of eugenic principles. As Sewell states,

*Most accounts of the origin of Britain's welfare state begin with the Minority Report of the Royal Commission on the Poor Laws, drafted by Sidney and Beatrice Webb during the first decade of the 20th century. Beneath their seemingly compassionate rhetoric, the founders of the Fabian Society were snobbish, elitist and harboured a savage contempt for the poorest of the poor. Both husband and wife were enthusiastic supporters of the eugenics movement, which held that most of the behavioural traits that led to poverty were inherited.*



(Sewell 2009: n.p.)

From a historical perspective attitudes and behaviours towards disability cannot be separated from the eugenic backdrop of welfare provision resulting in a continuation of underlying oppressive attitudes and behaviours. The Valuing People strategy (2001) states the terms “mental deficiency” and “mental sub-normality” reflected the underlying attitudes of the times yet it fails to even mention or acknowledge where these terms originate. Importantly policy makers by failing to raise awareness of how this negative terminology became common parlance and entered into the “collective unconsciousness” of negativity towards certain groups, missed an opportunity to address the undercurrent of eugenic attitudes towards people with learning disabilities.

As noted earlier most people with learning disabilities remain predominantly dependent on state benefits not least because of the lack of appropriate support and opportunities. This reinforces the negative stereotypes and attitudes that are already deeply ingrained and prevalent; moreover it reaffirms the belief that “they [are] a drain on resources” (Quarmby 2013:24) are seen as ‘scroungers’ and ‘scapegoats’ and results as Quarmby notes in a ‘them ‘versus “us’ distinction” (2013:185). Others who eugenicists similarly characterized negatively, blacks, Jews, lesbians and gay men, all shared the same fate from eugenic ideology in practice either at the hands of Hitler’s regime or the Americans. As Zimbardo’s *Stanford Prison Experiment* (McLeod 2008:np) clearly shows, the gap between creating the ‘other’ and exterminating him/her is not as great as we would imagine, or as far away either.

Elias highlights how individuals are perceived and valued “is intrinsically linked to value and meaning conferred by societal attitudes” (1996:353). In most cultures and throughout history, people with disabilities have been regarded as “inferior, dangerous, tragic, pathetic and not quite human” (Swain et al 2008:67). Even more so in fact after the Social Darwinists produced the pseudoscientific mantra of “survival of the fittest”. As stated earlier such negativity about disabled people has led to significant abortion rates of

'impaired fetuses' going unchallenged (Parens & Asch, cited in Swain et al. 2008) and the "compulsory sterilisation of people with learning disabilities" (Swain et al 2008:67) throughout the world. Eugenic ideology implemented in the MDA 1913 sought to segregate, and prevent procreation and is still effectively at work through the transmission of the belief systems in society. Wolbring (2001) is of the view that "today the main target of eugenic practices is the disabled body" (Swain et al 2008:103).

Recent austerity measures in reducing the costs of the welfare state, also a major theme for the eugenicists has revealed that cost cutting strategies are predominantly aimed at the sick and disabled. Following a number of Freedom of Information requests the Department of Work and Pensions have announced that between December 2011 and February 2014, 81,140 people died within one year of having changes made to their sickness or disability benefit status (Dept. Work & Pensions 2015). As Butler highlights "Nearly 90 people a month are dying shortly after being declared fit for work (2015: n.p.). Ministers are insisting that the data should not be used to link claimant deaths to welfare reforms they boldly state in the report "any causal effect between benefits (*withdrawal of*) and mortality cannot be assumed from these statistics" (Dept. Work & Pensions 2015:2). However Anita Bellows, from the campaign group Disabled People Against the Cuts, stated the group was "very worried by the number of people who died within two weeks of being found fit for work" (Butler 2015:n.p.). Other politicians have described the welfare reforms as a "punishing regime" (Burnham, cited in Butler 2015) which cause "immense distress and suffering for thousands of disabled claimants" (Corbyn, cited in Butler 2015). Whilst these figures alone do not convey a systematic negativity towards all disabled people, as many found "fit for work" were terminally ill, it seems strange that 90 deaths per month of sick or disabled people linked to cessation of benefits does not appear to be causing a national outrage, is this because as Sewell states "the influence of that (eugenic) thinking can still be seen today" (2008:n.p.)? Whilst eugenic thinking remains an un-discussed topic, the slow drip, drip, pernicious effects within society continue unabated. There is a continual and insidious, as Armer (2007) would describe it, "eugenetic" miasma which is polluting our belief

system.

Whilst the Chief Executive of the National Development team for Inclusion Rob Grieg has stated they are “seeking to reverse centuries of societal prejudice against people with learning disabilities” (Dept. of Health 2001:18). I would argue that without understanding and acknowledging the role and influence that eugenic ideology has had on the psyche of the populace, public perceptions are unlikely to change but may become more entrenched. As Elias notes, “generally speaking, the victims of history, the less powerful groups who have been defeated, have had only a small chance of being remembered” (1996:302), which means that much of the suffering individuals experience is not recorded or given sufficient air space to avoid the same mistakes being made.

To gain an understanding of the manner in which Armer’s miasma continues to pollute our belief system it is useful to now consider Bourdieu’s Theory of Practice.

## CHAPTER 5

### Bourdieu's Theory of Practice

*The central task of any social order is to convince its members that the current system of social stratification is legitimate*

*(Duster 2003:8)*

In seeking to understand the lives of people with learning disabilities it is critical to understand why they have consistently experienced social exclusion, poverty and limited life opportunities. As Jones notes “we risk a society where those who are viewed as different remain in the corners of society, not due to their disability but the way society views their disability” (2015:np). The origins of these views are considered in chapter 2.

In 2011 the BBC screened *Behind Closed Doors* a harrowing documentary of the experiences of people with learning disabilities being ‘cared’ for by the State. The Department of Health’s final report acknowledges “[t]he abuse revealed at Winterbourne View hospital was criminal” (2012:8). The scandal at Winterbourne View is indeed grim reading, but it also reveals much “wider issue[s] of how we care for children, young people and adults with learning disabilities or autism” (ibid) it notes many individuals with learning disabilities

*should not have been there in the first place, and in this regard the story is the same across England. Many people are in hospital who don't need to be there and many stay there for far too long, sometimes for years ...*

*Th[is] review has highlighted a widespread failure to design, commission and provide services which give people the support they need...*

*We should no more tolerate people with learning disabilities or autism being given the wrong care than we would accept the wrong treatment being given for cancer.*

*(Dept. of Health 2012:8)*

Yet we do tolerate this and we need to attempt to understand why. Following the Winterbourne scandal in 2010 and the resulting public outcry, the coalition government in 2012 committed to end inappropriate placements and treatment for individuals with learning disabilities or autism by June 2014 (McNicoll 2014). However in May 2015 there are still some 2600 people with learning disabilities or autism languishing in unsuitable inpatient settings (McNicoll 2015). As Steven Bubb of the Association of Chief Executives of Voluntary Organisation states, “over the past few years people with learning disabilities and or autism have heard much talk but seen too little action” (cited in McNicoll 2014:np). Seemingly a cultural neglect that we mostly collude with continues to pervade the lives of individuals with learning disabilities and autism.

In gaining an understanding as to how and why the unacceptable conditions and poor life opportunities discussed in this thesis are allowed to perpetuate, I suggest it is pertinent and useful to engage with Bourdieu’s theory of practice (1977). According to Kitchen “the practice of using Bourdieu to examine institutional change is still in its infancy” (2014:36) not least because of its perceived complexity and challenging ideology. Whilst it is acknowledged by Sulkunen that Bourdieu’s style is “complex, literary and difficult” (1982:106) Garrett states that the “social professions should critically engage with the work of Pierre Bourdieu” (2007:225) even though he too, recognises it is often difficult and complex. Lizardo on the other hand states Pierre Bourdieu “is without doubt one of the main figures in the sociological study of culture today” (2010:1). Straddling the disciplines of anthropology and sociology, his “work points towards a yet to be developed post cultural stance” (Lizardo 2010:5). In recognition of Bourdieu’s importance to current debate, Edles introduces Bourdieu as “the most influential theorist in the world today” (2002:224). In his theory of practice Bourdieu introduces a radically different concept of what culture is, how it works and importantly how it is transmitted, acquired and reproduced. This concept, described by Maton as “enigmatic” (2008:49), could offer an explanation for the collusion of the “criminal” treatment mentioned in the report into Winterbourne View hospital (Dept. of Health 2012).

This radical concept, stemming as it does from an anthropological and sociological fusion, sets out to blend two major intellectual accounts of culture and society, which exist in parallel, notably existentialism and structuralism. Until Bourdieu produced what Wacquant describes as “an original conceptual arsenal” (1998:220) the perspectives of existentialism and structuralism were considered in academic traditions as discordant or incompatible (Wacquant 1998). Wolfreys (2000) and Swartz (2013) note that Bourdieu’s project was to overcome the opposition between the subjectivist emphasis on individual consciousness (existentialism) and the objectivist’s preoccupation with social structures (structuralism). These elements in many ways replicate the position in social work practice between the psychodynamic approaches of Freud and Pearlman based on individual causation and the more structural radical approach taken by Leonard and Mullaly. The influences of existentialism found in the works of Sartre focused heavily on the ‘choices’ of individuals which Garret states is “a theory of agents without acknowledging the impact of entrenched structures” (2007:227); alternatively critiques of structuralists such as Althusser, suggest they are “producing a grand theory without agents” (ibid). Bourdieu’s theory of practice which introduced the concepts of ‘habitus’ ‘capital(s)’, ‘field’ and ‘doxa’ is seen to transcend the oppositions between the individualism of existentialism and the structures (structuralism) of society and to embrace a more holistic approach to account for the actions and experiences of individuals in the social world.

As Sulkunen highlights, Bourdieu’s theory of practice brings to the fore the “unconscious function of the total society” (1982:105). By linking together the “choices” of individuals and the structures of society, Bourdieu’s focus on this interplay, from what are seemingly divergent areas, is able to offer an explanation for the ways in which behaviours, attitudes, lifestyles, and values are imbibed by the individual in a manner which produces and contributes to the way individual lives and structures are played out in society. Moreover “[Bourdieu’s] problematic consists in revealing and bringing to light the hidden forms of domination that are consciously and unconsciously reproduced in



everyday life” (Sulkunen 1982:108). This is a factor that is particularly relevant for people with learning disabilities and will be explored later.

Stemming from his work as an anthropologist and sociologist the methodological eclecticism of Bourdieu “brings to light social structures” or cultures “that social theorists are usually only able to describe in the abstract” (Sulkunen 1982:107). In essence Bourdieu’s theory of practice “weaves into existence an understanding of social life which amalgamates a structural approach with an existentialist perspective to the lived experience” (Lizardo 2011:18).

### Concepts: Habitus

To gain a clearer understanding of the insight Bourdieu’s “original conceptual arsenal” brings, it is helpful to explore the aspects of ‘habitus’, ‘capital(s)’, ‘field’ and ‘doxa’. According to Zeuner,

*Bourdieu understood culture to be everything which is intuitively understood, self-evident and unspoken, and which it is difficult to objectify. It is everything one has learnt at one’s mother’s knee, in the pre-verbal stage (2003:179).*

He further adds that for Bourdieu ‘culture’ is effectively a large scale social mythology, but one nonetheless that is “intuitively understood” (Lizardo 2010:7). For Bourdieu culture is not so much a set of social rules but an adherence to “deeply internalized habits, styles and skills” (ibid) which are created in the ‘habitus. Although ‘habitus’ is claimed to be “one of the most misunderstood, misused and hotly contested of Bourdieu’s ideas” (Maton 2008:49), Garrett (2007) and others (Hillier & Rooksby 2002) acknowledge that ‘habitus’ is the reformulation of an idea which has a deep philosophical and sociological history, even though they suggest that the concept of ‘habitus’ is difficult to “pin down” (Hillier & Rooksby 2002:377). Reay also suggests that ‘habitus’ “is probably Bourdieu’s most contested concept” (2010:432), yet Bourdieu regards the concept as central to his view of ‘structuralist constructivism’. For Bourdieu the ‘habitus’ transcends the opposites between an individual and society, and provides a mechanism to

understand how “human action is regulated” (Swartz 2002:64). In an interview with Eagleton in 1992, Bourdieu explained ‘habitus’ as a “set of acquired dispositions that reflect the history of a person and a place” (Bourdieu & Eagleton 1992:111). Garrett describes habitus as something “laid down in each agent from the earliest upbringing and reverberates through[out] a person’s life” (2007:231). Bourdieu himself describes it thus,

*The habitus is a set of dispositions, reflexes and forms of behaviour people acquire through acting in society. It reflects the different positions people have in society [and] it is part of how society reproduces itself.*

*(Bourdieu 2000:19)*

These behaviours, attitudes, values and dispositions, are imbibed into individuals little by little, “through a myriad of mundane processes of training and learning” (Thompson in Bourdieu 1991:12). Therefore they are structured in the sense that they inevitably reflect the social position or structure of acquisition. Consequently the ‘habitus’ becomes ingrained in the individual by being absorbed “informally through the experience of social interaction, repetition, role-play and game participation” (Swartz 2002:22). In turn these ingrained customs and practices represent the habitus from which they emerged and effectively become “history incarnate in the body” (Bourdieu 1994:190). Not only do they encapsulate structures and ideologies of history in individuals they become embodied in ways of walking, talking, and being, thereby encrypting society’s views into the body (Garrett 2007, Reay 2004). As Bourdieu states

*All the products of a given agent, by an essential over-determination, speak inseparably and simultaneously of his [her] class- or, more precisely, his [her] position in the social structure and his [her] rising or falling trajectory and of his or her body or, more precisely, all the properties, always socially qualified of which he or she is the bearer*

*(1977:87)*

Habitus, although internalised predominantly unconsciously, (particularly during childhood) offers opportunities or constraints common to the membership of one’s particular social class or grouping. It therefore adjusts

aspirations or expectations and “predisposes actors to select forms of conduct most likely to succeed in light of their resources and past experience” (Swartz 2002:22). As Sulkunen suggests, the ‘habitus’ entrenches the various practices associated with living within certain group or class settings whereby these practices become “harmonized and homologised,” in essence a “modus operandi” (1982:108). However Bourdieu reports that the system itself camouflages the thousands of ways in which the ‘habitus’ reproduces difference, as difference is attributed to ‘innate’ qualities. Bourdieu suggests that in reality this difference is reflected in the domination of certain groups over others, producing “an aura of legitimacy to the values, tastes and life style of dominant classes” (Sulkunen 1982:104). Whilst Goffman’s (1951) work introduced the concept of “sense of one’s place”, similarly, ‘habitus’ facilitates and enables one to have a sense of place both at an individual level but also in the social order, this creates an often unconscious “understanding of inclusion and exclusion in the various social hierarchies” (Swartz 2002:22). By internalising through the ‘habitus’ our basic life chances we become aware of what is “possible, impossible and probable for people of [our] kind” (op-cit). Moreover, an individual “is never more than a deviation from his or her collective reference” (Swartz 2002:22). This sense of one’s place created within the ‘habitus’ can and often does lead us to exclude ourselves from goods, persons and places from which we are not familiar.

In essence the ‘habitus’ “is a property of social agents, whether individuals, groups or institutions” (Maton 2008:51) and comprises of a “structured and structuring structure” (Bourdieu 1994:170). As Maton describes, the ‘habitus’

*is structured by one’s past and present circumstances, such as family upbringing and educational experiences. It is structuring in that one’s habitus helps to shape one’s present and future practices. It is a structure in that it is systematically ordered rather than random or unpatterned. This structure comprises a system and dispositions, which generate perceptions, appreciations and practices.*

(2008:51)

Therefore in relation to all of us, but in particular for people in the research group with a history of oppression underpinning their life experiences, it can

be seen how the 'habitus' can affect "ways of acting, feeling, thinking and being" (Maton 2008:52).

*By its very nature our 'habitus' "captures how we carry within us our history, how we bring this history into present circumstances, and how we then make choices to act in certain ways and not others. This is an on-going and active process; we are engaged in a continuous process of making history, but not under conditions entirely of our own making. Where we are in life at any one moment is the result of numberless events in the past that have shaped our path.*

*(Maton 2008:52)*

Marx also noted in *The Eighteenth Brumaire of Louis Bonaparte*, individuals "make their own history, but they do not make it as they please; they do not make it under circumstances chosen by themselves, but under circumstances directly encountered, given and transmitted from the past" (cited in McLennan 2000:329). More recently Reay states "habitus is primarily a method for analysing the dominance of dominant groups in society and the domination of subordinate groups.... [it] can be used to focus on the ways in which the socially advantaged and disadvantaged play out attitudes of cultural superiority and inferiority ingrained in daily interactions" (2010:436). As Sulkunen explains "those with the largest pools of cultural capital, the intellectuals constantly create new tastes, styles and aesthetic values and claim legitimacy for them" (1982:106).

Although the concept of 'habitus' provides for an understanding of how we learn "our rightful place in the social world" (Maton 2008:58), especially given our circumstances and attributes, or lack of them, this alone does not give the full overview or explain the perpetuation of the unacceptable experiences reported in the review of Winterbourne View hospital or the experiences of the participants in this research. To understand this we need to consider 'habitus' alongside the other aspects of Bourdieu's theory of practice. Bourdieu for his part repeatedly considered the question of how and why individuals think and behave in the ways that they do (Maton 2008) and suggests that

*social reality exists, so to speak, twice, in things and in minds, in fields and in habitus,*

*outside and inside social agents. And when habitus encounters a social world of which it is the product, it is like a 'fish in water': it does not feel the weight of the water and it takes the world about itself for granted.*

*(Bourdieu & Wacquant 1992:127)*

Importantly Bourdieu noted the importance of the compatibility between the 'habitus' individuals have absorbed and the "field(s)" in which they attempt to live out their lives. It is therefore appropriate to now consider the 'field(s)' of Bourdieu's theory.

### Concepts: Field

For Bourdieu, it is the various interactions between habitus, capital and field that creates his conceptual toolbox. As he says

*The relation between habitus and field operates in two ways. On one side, it is a relation of conditioning: the field structures the habitus, which is the product of the embodiment of the immanent necessity of the field (or of a hierarchy of intersecting fields). On the other side, it is a relation of knowledge or cognitive construction: habitus contributes to constituting the field as a meaningful world, a world endowed with sense or with value, in which it is worth investing one's energy.*

*(Bourdieu, in Wacquant 1989:44)*

What exactly is meant by a 'field' in the context of Bourdieu's theory of practice? In essence a field (*le champ*) is 'a structured social space, a field of forces' (Bourdieu, 1998:40) with agents and groups of agents being defined by their relative positions in this space. Perhaps a clearer understanding of this is that 'field' or 'fields' are distinct but often overlapping social spaces, such as the field(s) of for example, politics, education, family, law, the media, social work and science. Sulkunen describes "everyday life [a]s a conglomeration of 'fields' – leisure, family patterns, consumption, work [and] artistic practices" (1982:106). For Bourdieu all social interactions revolve around a complex interface between individuals and or groups within social fields. Within each field(s) there also exists a hierarchy of position, decided on by possession of various elements of what Bourdieu refers to as 'capital'; therefore in line with the respective 'capital' accumulated, individuals and groups will occupy dominant or subordinate positions (Naidoo 2004).

As Kitchen further notes, “a field is a distinct and objective social space (field space) that consists of networks of relations between agents” (2014:38). In practice a field consists of a structured system of social positions in which agents both exist and compete with other agents for resources, stakes and access (Bourdieu, 1990). Ultimately any ‘field’ position in regards to subordination or domination an agent (individual or group) finds themselves in, is largely determined by their relative access to ‘capital’ and their own ‘habitus’, with many, especially those who are part of the subordinate group feeling, to utilise Bourdieu’s analogy, like a fish out of water in many situations. In relation to understanding the importance of the role of the conceptual ‘field’ Thomson explains that in understanding social phenomena or finding an explanation of events, such as the Winterbourne View scandal or what the research group has shared, it is necessary to look beyond what has been said or what happened; it is important to consider it within the “social space in which interactions, transactions and events occur” (2008:67). As Bourdieu suggests, it is necessary to consider events within the specific historical, local, national or international context, of the event and the manner in which so-called ‘knowledge’ about any group or individuals has been arrived at. Moreover it is important to take a critical gaze into the ways in which that specific knowledge has been generated, by whom and who is benefitting from it. This is particularly relevant given the backdrop of eugenic ideology, which here is being viewed in relation to people with learning disabilities.

As has been stated already the social space or ‘field’ is part of the conceptual trio of habitus, capital and field that reflects an overarching conceptual approach that moved away from what Thomson refers to as the “aimless debates about the primacy of either social structures or human agency” (2008:69), earlier referred to as the existentialism and structuralist debate. The integration of these three concepts is critical to understanding the social world and each agent’s place within it. Different authors (Thomson 2008, Crossley 2004) give differing analogies of the term ‘field’, at times a field being likened to a market or a game (Crossley 2004), or to a force field or a football



field (Thomson 2008). Bourdieu himself states that social fields “are therefore, so to speak, games ‘in themselves’ and not ‘for themselves’ one does not embark upon the game by a conscious act” (1990:67), suggesting that fields are entered into to engage in the social world, but akin to a market they are places of competition where people jostle to maintain or improve their position (Thomson 2008) through the exchange of capital resources. As Bourdieu notes, each field “contains people who dominate and people who are dominated” (1998:40).

### Concepts: Capital

Operating within each field is the accumulation of the various types of capital which Bourdieu has described as: economic (money and assets); cultural (knowledge, taste, aesthetics, e.g. art, music choices, dress code); social (families, networks, affiliations, religious groups, club memberships); and symbolic (notably credentials/educational achievements) which can be utilised and exchanged for other types of capital in the field (Thomson 2008, Crossley 2004). Unfortunately as Thomson highlights “there is no level playing ground in a social field” (2008:69) so those who are advantaged from the outset by having accumulated capital from their respective habitus are inevitably engaged in retaining their position of domination within the social field. Kitchen (2014) reaffirms Bourdieu’s stance that capital is essentially a euphemism for power, “whereby the different types of capital (or power, which amounts to the same thing) change into one another” (Bourdieu 1986:np). Kitchen states,

*Power in Bourdieu’s work is expressed as capital, the forms of which are field-specific. Certain types and volumes of capital are required by agents to contest for field positions from which power can be wielded over those they dominate.*

*(Kitchen 2014:30)*

The role of capital as a means of power is self-explanatory, as one of the key issues for Bourdieu was how and why relationships of inequality and domination continue. In today’s climate with increased levels of inequality this concern remains unabashed and in the main unchallenged. Bauman

describes it thus

*Those tenets of injustice are tacit (implicit) premises underpinning and pretending to make sense of the loudly voiced (explicit) convictions, but they are hardly ever reflected upon and subjected to tests; they are always intimated, but seldom articulated beliefs with which we think- but of which we do not think (2013:20)*

Crossley (2004) refers to this concern as a “central focus upon the relationship between culture and power”, reaffirming that capital is itself a mode of power, which can be utilised effectively in a range of fields or social spaces. Bourdieu himself notes, “permanent relationships of inequality operate within this space” (1998:41). Of further concern to Bourdieu was the manner in which these inequalities appear to be natural and fair, yet he was “unequivocal that some fields are dominant and others subordinate” (Thomson 2008:80). To this end he considered that his theory of practice, which has also been described above as his conceptual tool kit for analysis, is a methodology which could produce different ways and means of understanding the social world, one which would recognise the inequalities inherent in the current status quo - hence the potential benefit of this model to the social work profession.

To consider why the inequality and domination of certain groups and individuals appears to be natural and fair is where we will now turn. Bourdieu noted that

*It is in fact impossible to account for the structure and functioning of the social world unless one reintroduces capital in all its forms and not solely in the one form recognized by economic theory.*

*(Bourdieu cited in Richardson 1986:242)*

Moreover Bourdieu recognised that capital in its various forms ultimately shaped and formed life opportunities and life styles. He suggested the transmission of capital occurred in three ways: in what he called the ‘embodied state’, through long lasting dispositions of the mind and body, transmitted through the way we walk, talk, interact and think; in the ‘objectified

state' via cultural artifacts such as books, pictures, dress codes and forms of music; and in the 'institutionalized state' a form of rules procedures and actions which are given legitimation by the dominant discourse.

As he explains,

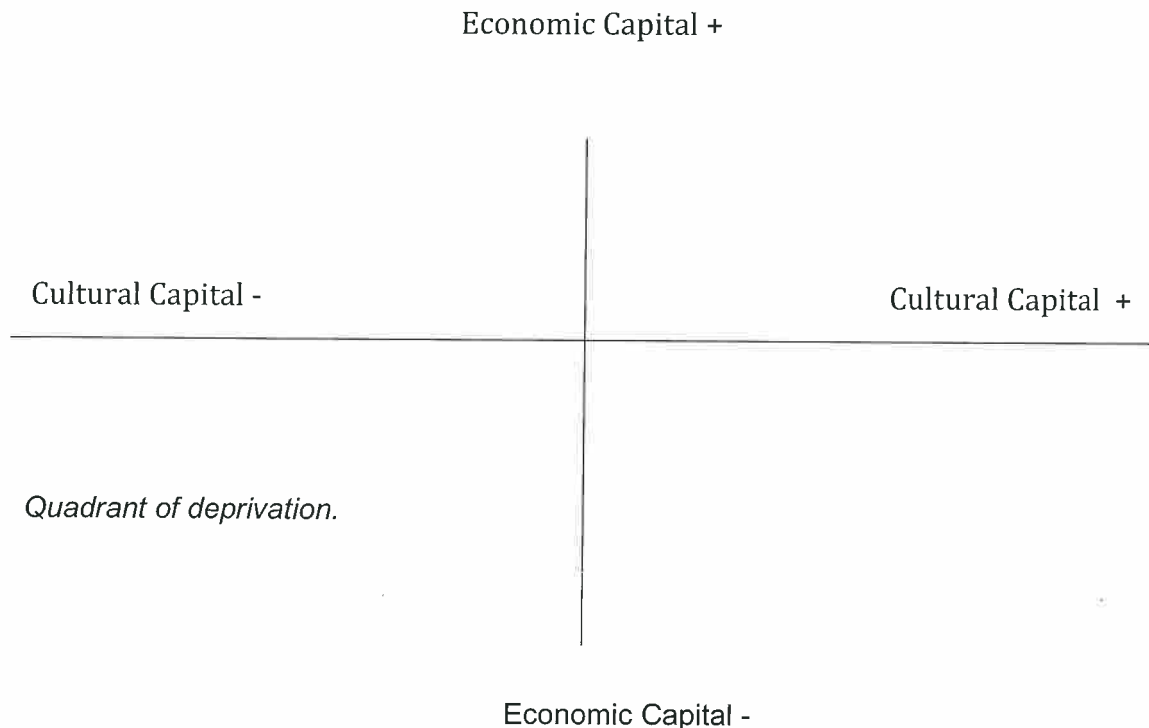
*[C]apital possessed by a given agent thus depends on the size of the network of connections he can effectively mobilize and on the volume of the capital (economic, cultural or symbolic) possessed in his own right by each of those to whom he is connected; by the same token, it reaffirms the limits of the group, i.e., the limits beyond which the constitutive exchange – trade, commensality, or marriage – cannot take place. Each member of the group is thus instituted as a custodian of the limits of the group.*

*(Bourdieu cited in Richardson 1986:248)*

Given these pre-requisites for gaining and maintaining power, notably through the exchange of 'capital' in social spaces referred to as 'fields' it is becoming apparent why inequalities exist and why the "criminal" treatment of people with learning disabilities has continued up to and including the present day.

If capital resources are considered in the social field in the diagrammatical form suggested by Thomson (2008:72), it is apparent that ones societal position is related to factors of capital accumulation and social positioning within the field (social space).

Diagram of a social field (adapted from Thomson)



In addition to the elements Thomson (ibid) refers to I have added a quadrant of deprivation which reflects the low acquisition of capital in either cultural or economic capital within the field. Given the opportunities (or lack of them) afforded to people with learning disabilities and the values created by the dominant 'habitus' of people with learning disabilities it can be seen that they will inevitably fall into the quadrant that is both low in cultural and economic capital. This can partly be explained as Mullaly states by the "biological determinism [that] is still used by dominant groups to legitimate domination and social inequality" (2002:39), a factor influenced historically by eugenic ideology. I suggest this 'quadrant of deprivation' is the starting point of a range of life time inequalities experienced by people with learning disabilities. I will further be suggesting that this position has been arrived at through what Bourdieu terms as 'doxa', these doxic assumptions are inherent in society via eugenic ideology.

### Bourdieu & Doxa

What does the term 'doxa' really mean? Although the ancient Greek meaning describes it as opinion, Bourdieu's understanding and use of the term differs significantly from other writers (Deer 2008:119). Whilst Bourdieu adopted the Husserlian concept of doxa in that he used the meaning to represent 'everyday knowledge' or 'taken for grantedness', as opposed to its' original meaning in Greek which meant opinion. Waldenfels (1982) suggests that for Husserl "doxa receives a privilege status over against the insights of science" (1982:26). In as much as it is the 'living truth' and permeates all spheres of our lives. Husserl's use of doxa "tries to show how order and rationality arise and transform themselves in experience" (Waldenfels 1982:31). Doxa in Bourdieu's usage has a number of related meanings and types of understanding,

*[T]he concept broadly refers to the misrecognition of forms of social arbitrariness that engenders the unformulated, non discursive, but internalised and practical recognition of that same social arbitrariness.*

*(Deer 2008:120)*

Doxa was used by Bourdieu to explain what are seemingly 'natural' practices and attitudes which rather than being 'natural' are in fact taken for granted assumptions and beliefs which are so entrenched in the mind sets of individuals that they become the 'givens' in society (Bourdieu 1977). Fanon describes this in terms of the collective unconsciousness (1986) and Mullaly notes "through the process of socialization, dominant ideologies become so ingrained that we consider them to be taken for granted views or common sense knowledge" (2002:23). Deer also notes that doxa refers to "pre reflexive intuitive knowledge, shaped by experience to unconscious inherited physical and relational dispositions...shared but unquestioned opinions and perceptions" (2008:120). As Kitchen suggests, doxa are 'regimes of truth' that represent values and discourses which represent the fundamental principles of a field and are thus taken for granted" (2014:44). Moreover as Chan elaborates,

*The social conditioning of the doxa is a shared experience for each agent within the group. This experience creates an illusion of spontaneous understanding and a tendency to conform to a specific set of values and discourses, which, if applied to the dominant group within the field, are viewed as inherently true and necessary*

*(Chan cited in Kitchen 2014:45).*

As a result doxa becomes the epitome of the undisputed and the un-discussed; this is because doxic assumptions are so deeply ingrained through the experiences of habitus, capital and field that they do not merit surfacing for questioning. This orthodoxy, the doxa of those who are dominant, ‘essential[ly] goes without saying because it comes without saying’ (Bourdieu 1977:167). The views of the powerful ‘reflects the official history of the field’ (Kitchen 2014:44), or as Bourdieu describes “everything seems obvious and [therefore] goes without saying” (1998:81). Deer reaffirms this view by stating it is “a reality that goes unanimously unquestioned because it lies beyond any notion of enquiry” (2008:120). As Bourdieu & Wacquant have highlighted, “the mutual reinforcement between field and habitus strengthens the prevailing power of doxa” (Deer 2008:121), enabling doxa to take the form of symbolic power, thereby replacing physical forces of control with seemingly ‘natural’ implicit strengths and legitimacies.

In contrast to doxa, which is presented as the natural, taken for granted way of being; Moi (1991) comments that

*[D]oxa is to be distinguished from orthodoxy (the effort to defend doxa) as well as heterodoxy (the effort to challenge the doxa) insofar as these two positions more or less recognize the possibility of different arrangements. To defend the ‘natural’ is necessarily to admit that it is no longer self-evident.*

*(Cited in Kitchen 2014:38)*

Therefore it can be seen that doxa is utilised as a concept by Bourdieu to explain the seemingly ‘natural’ and ‘legitimate’ forces of domination of subordinate groups. Particularly as a force of symbolic power, doxa “requires that those subject to it do not question its legitimacy or the legitimacy of those who exert it” (Meer 2008:123).



In this regard therefore I suggest it is of use for social workers to understand Bourdieu's theory of practice and particularly the taken for granted-ness of the unspoken, un-discussed, beliefs, practices and assumptions, which I suggest emanate from eugenic ideology. Moreover as agents of empowerment, within the context defined by Mullaly as "a process whereby social workers would give power to the people with whom they worked" (2007:298), social workers need to familiarize themselves with the role doxa plays in the symbolic violence inflicted on people with learning disabilities through their respective habitus, field and opportunities for the accumulation of capital. As Bourdieu suggests

*[S]ocial workers must unceasingly fight on two fronts: against those they want to help and who are often too demoralized to take a hand in their own interests, let alone the interests of the collectivity; on the other hand, against administrations and bureaucrats divided and enclosed in separate universes.*

*(Bourdieu et al, 2002:190)*

## CHAPTER 6

### A Feminist Narrative Methodology

*These were forgotten people, leading forgotten lives so that telling their stories became a social and historical imperative (Grant et al 2010:8)*

Storytelling is part of the human condition and it has been the method by which history, knowledge, beliefs and truths are passed from one generation to another. In the Christian tradition storytelling is the basis of the on-going spiritual belief system documented by the prophets and by the gospel writers. As Bamberg notes, “stories and storytelling practices are assumed to be closely tied up with the phylogenesis of language, human social formations and the historically emerging vision of individuality and the modern person” (Bamberg 2012:6). He also acknowledges that narrative form reaches “back as far as 1500 BC” (ibid). Narrative enquiry, as Savin-Baden and Van Niekerk suggest, is “an approach that focuses on the use of stories as data” (2007:460). Narrative enquiry set within a qualitative research paradigm seeks “to grasp phenomena in a holistic way, to understand phenomena within context, or to emphasise immersion in and comprehension of human meaning” (McCue: 2012: 4). Narrative is described as,

*Grounded in hermeneutics, phenomenology, ethnography and literary analysis, narrative research eschews methodological orthodoxy in favour of doing what is necessary to capture the lived experiences of people in terms of their own meaning making and to theorise about it in insightful ways.*

*(Josselson cited in Wertz et al 2011:225)*

Currently “narrative has acquired an increasingly high profile in social research” (Andrews et al 2013:1). Whilst it seems to have popularity and is much discussed, its definition is in dispute (ibid). It is alleged, “narrative research offers no overall rules about suitable materials or modes of investigation” (ibid). However since narrative approaches experienced a “crest of popularity [it] is now becoming a discipline in its own right... developing

distinctive methods of data collection, processing and analysis” (Holstein & Gubrium 2012:3).

### Story Telling

Set within a qualitative paradigm that Gomm suggests is “often a hand to mouth, flying by the seat of your pants activity” (2008:22); the utilisation of a narrative approach enables the investigation of an otherwise often hidden story and history of individuals who are expert witnesses in their own lives. Narratives can also enable us “to understand more about individual[s] and social change [and] carry traces of human lives that we want to understand” better (Andrews et al 2013:3). Furthermore, this approach facilitates the recognition of individuals with learning disabilities as being the full rounded human beings they are, and enables the issue of the historical backdrop to be investigated (Grant et al 2010). As Atkinson notes “on the whole, people with learning disabilities were silent and invisible in the historical accounts of learning disability policy and practice (cited in Grant et al 2010: 8). As “forgotten people leading forgotten lives” Atkinson reminds us that “telling their stories [has] become a social and historical imperative” (Atkinson in Grant et al 2010:8).

It is appropriate therefore in order to encapsulate a rounded account of people’s individual experience that the narratives of those with stories to tell can be heard. Narrative research provides a process for this to be achieved as it allows and facilitates an opportunity to gain insight to these lived experiences. “Commonly shared beliefs about who we are, or who we think we are, [are] realised in the stories we tell about ourselves; everyone not only has a story but also has a right to tell their story” (Bamberg 2012:6). Llangellier adds, “embedded in the lives of the ordinary, the marginalised, and the muted, personal narrative responds to the disintegration of master narratives as people make sense of experience, claim identities and get a life by telling and writing their stories (2001:700). Others add that narratives can also be used as “modes of resistance to existing structures of power” (Andrews et al 2013:4) alternative stories heard and shared can question the legitimacy of the official story.

It is recognised there are many definitions and varieties of narrative research that can include a range of artefacts such as photographs, letters, diaries and other accounts such as told or recorded life stories (see Andrews et al). Whilst there are variations in definition of narrative the common theme within this approach is that “narratives represent storied ways of knowing and communicating” (Hinchman & Hinchman cited in Riessman 2003:1).

### A Feminist Perspective

Minichiello & Kottler note the feminist approach was developed in rejection of the positivist, “supposedly objective and empirical” (2010:24) paradigm that had existed in research. Set within a postmodernist frame of reference that contends ‘truth’ or cause-effect has a multitude of causes and that “reality is often fragmented, indeterminate and chaotic” (ibid); feminist research sought to focus on issues such as oppression, inequality and dominant patriarchal discourses within society and sought the sharing of views from a non hierarchical relationship via stories and narratives. This approach is reflected in these extracts from the JUCSWEC Code of Ethics for Social Work and Social Care Research (2008) which states:

*Where possible, seek to empower service users...*

*Seek to promote emancipatory research, and work together with disempowered groups, individuals and communities to devise, articulate and to achieve research agendas that respect fundamental human rights and which aim towards social justice...*

*Social & social care researchers should seek to predicate their work on the perspective and lived experiences of the research subject. (JUCSWEC 2008)*

Narrative research lends itself well to a feminist perspective, as it too has emancipatory aims (Andrews et al 2013). Moreover a feminist perspective has “resisted the notion that personal narratives [are] merely informational” (Holstein & Gubrium 2012:2). Hesse-Biber highlights that “Jacobs demonstrates how the concrete lived experience is a key place from which to build knowledge and foment social change” (2011:18.). Moreover these authors highlight that a feminist perspective will carry messages of

empowerment that can challenge the status quo, creating knowledge from an alternative base, from voices often not heard and not just from those who occupy privileged positions. As Hesse-Biber states “Feminist thinking and practice require taking steps from the “margins to the centre” while eliminating boundaries that privilege dominant forms of knowledge building, boundaries that mark who can be a knower and what can be known”(ibid).

The approach taken here is also one Schutt describes as “participatory action research” viewed through a narrative lens (2009:558). Gomm (2008: 333) would consider this to be partisan research where the researcher has a “particular expertise in making moral judgements about social arrangements and attempting to change them.” As he notes “they usually draw their mandate for this from representing themselves as researching on behalf of a constituency of oppressed people such as women, black people, working class people, gays, disabled people and so on who deserve to have their concerns articulated by a researcher” which he suggests is “another moral judgement” (ibid). In this research however I make no apologies for taking an anti- oppressive moral stance that is in keeping with my Social Work ethical perspective and therefore I have claimed some special skill as a social worker in deciding that this research is required as a moral and ethical matter. Gomm is likely to purport that this is an exercise relying more on perceived “expert judgement” than on the “rigorous use of social scientific methodologies” (2010:329). However this work incorporates a feminist perspective and the methodology of “feminist research differs from traditional research, [because] it actively seeks to remove the power imbalance between research and subject; it is politically motivated in that it seeks to change social inequality” (Brayton et al 2015: np).

According to Westmarland “knowledge has traditionally been measured by how objective it is deemed to be, in the belief that if the reliability, objectivity and validity “rules” are followed “the truth” will be discovered (2001:np). In regarding what is taught as acceptable evidence Mee highlights the notion of this as emanating from such ‘truth’ sources as “randomised controlled trials, strong evidence from well-designed trials without randomisation, non

experimental studies from more than one research group and opinions of respected authorities” (2012:15). Further he suggests that “first hand accounts from those who are not respected and this includes from people with learning disabilities” (2012:16) do not generally equate with a rigorous methodological approach. Nonetheless, as Smith acknowledges, “the source of understanding is the ‘lived experiences’ of individuals” (cited in Mee 2012:15). Moreover Mee confirms that the “story provides a basis for generating an understanding of the whole” (2012:15). Citing Bolton, he notes “stories and poems are slices, metonymically revealing the whole of life” (2006:205). In contrast to his views on perceived wisdom gained through “rigorous social scientific methodology”, throughout his text on *Valuing people with a Learning Disability*, Mee utilises “stories” to explain the various issues he explores, notably the manner in which people with learning disabilities continue to be marginalised, ostracised and discriminated against.

In summary the approach here is narrative methodology from a feminist perspective, intertwined with an advocacy /participatory, or partisan, as Gomm would call it, and a social constructionist view. It is important to note here that a feminist approach is a perspective and not a research method as feminist researchers utilise a number of differing research methods. Taking these approaches one by one, an advocacy/participatory view “holds that research enquiry needs to be intertwined with politics and a political agenda [and] thus the research contains an action agenda for change” (Creswell 2009:9). This view addresses specific important social issues, for example inequality, oppression, suppression and alienation (Creswell 2009). Likewise the social constructivist view recognises that the researcher’s own background shapes their interpretation and acknowledges “their interpretation flows from their [own] personal, cultural and historical experience” (Creswell 2009:8). For advocacy /participatory researchers there is undoubtedly a strong stimulus to pursue topics that are of personal interest; issues that relate to marginalised people, and an interest to create a better society for everyone (Creswell 2009:19). As Andrews et al. further note, narrative researchers’ ‘own stories’ are relevant and these in turn need to be acknowledged, as others’ stories are also shaped by their listeners, (2013:7)



Josselson explains

*Narrative research is an interpretive enterprise consisting of the joint subjectivities of researcher and participants subjected to a conceptual framework brought to bear on textual material either oral or written by the researcher. (Wertz et al 2011:225)*

Additionally, Mishler notes “narrative telling is not mimetic; it is not an exact representation of what happened, but a particular construction of events created in a particular setting, for a particular audience, for particular purposes, to create a certain point of view” (Mishler 2004 *ibid*).

For Gomm therefore a narrative approach is likely to carry with it an allegation that what is being presented as “a matter of fact is really a moral judgement” (Gomm 2008:333). However,

*Feminist research practitioners pay attention to reflexivity, a process whereby researchers recognize, examine, and understand how their social background, location, and assumptions affect their research practice. (Hesse -Biber 2012:17)*

Ramazanoglu notes “it is more logical to accept our subjectivity, our emotions and our socially grounded positions than to assume some of us can rise above them” (1992:211). Westmarland also adds “Humans, be they female or male, are not computers, and are unable to process information without some degree of subjective interpretation” (2001:n.p.) and highlights “identifying the topic to be studied invariably involves subjectivity” (*ibid*).

Riessman also highlights that social structures, governments and media representation create or construct “preferred narratives about history” (2003:1) or cultural and social ‘truths’. An example of this social construction is exemplified by the hagiography of the former Conservative Prime Minister Margaret Thatcher; given a state funeral in 2013, for her significant contribution to the UK, Therborn highlights that from the usual accolades “one of her important achievements [is] usually missing: [notably the] trebling of child poverty in the UK, from 7% in 1979 to 24% in 1992” (2013:18). An alternative narrative of this famous or infamous individual, depending on one’s

perspective, or social construction would be the graffiti painted on the London City Mission, a building close by London Bridge station viewed daily by commuters, which read “the witch is dead but the spell remains” (2013). This graffiti appeared alongside the Anti-Thatcher campaign to promote the song from the film the Wizard of Oz (1939) “Ding Dong the Witch is Dead” to the number one place in the music charts, it failed to achieve this but the song reached the 2<sup>nd</sup> place and attempts were made by politicians to prevent this song from being played on the radio in the weekend chart show (BBC news 12/4/13). This issue highlights that what is presented in a hagiographical manner as historical truth, or to utilise Gomm’s phraseology “a matter of fact” (2008:333) is actually a narrative of a particular social construct, from a particular discourse that is not necessarily a factual record of what really happened or what the alternative views may have been. (Spence cited in Wertz et al 2011:225) As Scotland notes “realities are [also] socially constructed entities” (2012:13).

A feminist perspective within a narrative frame of reference is particularly appropriate for this study. As methodologically “it actively seeks to remove the power imbalance between researcher and subject; it is politically motivated in that it seeks to change social inequality” (Brayton et al 2015:n.p.). Hesse-Biber adds, “most feminist researchers seek to connect their research to social transformation and social change on behalf of women and other oppressed groups” (2012:18). Moreover the methods utilised in my research “such as intensive interviewing, the collection of oral histories, and qualitative data analysis are often labelled feminist methods” (Hesse-Biber 2012:19).

In narrative inquiry, researchers need to listen to a participant’s story, acknowledge the mutual construction of the research relationship and recognise that the story is part of the storytellers’ individual being (Savin-Baden & Van Niekerk 2007). It seems that the narrative approach has been embraced and touched by many professions and “narrative analysis takes as its object of investigation the story itself” (Riessman 2001:3). As Andrews (2013:7) has stated earlier how a story is told and how it is heard are also shaped by life events and social constructions and this too needs to be

acknowledged. Within a feminist perspective, these aspects of the researcher are also recognised. Narrative research allows for the voices of participants to be captured and presented (Savin-Baden & Van Niekerk 2007) as a valuable and unique resource; importantly “the personal troubles [accounts] that participants represent in their narratives, tell us a great deal about social and historical processes” (Riessman 2001:4). Referring to Mills, Riessman states, “what we call personal troubles are located in particular places, and individuals’ narratives about their troubles are works of history, as much as they are about individuals, the social spaces they inhabit, and the societies they live in” (Riessman 2001:4). Given the historical perspective of this research, the social spaces inhabited and the individual experiences of people with learning disabilities sought in this thesis, a narrative approach is extremely suitable.

Gomm would argue this thesis has a critical research perspective, stating it is addressing “private troubles” and raising issues considered as “social evils” the feminist writer Carol Erlich calls this “muck-raking research” (cited in Gomm 2008:333). Lee aptly suggests if muckraking sociology is a research style that seeks to “uncover what the powerful, for their own ends, wanted to keep hidden” (1993:14) then this description also fits that category.

It is stated those who lack power are more often the subjects of research than those who possess it (Walford 1994, Lee 1993). Originally this thesis had proposed to interview social workers, however time constraints and non availability or willingness of subjects meant this dimension had to be abandoned. Whether this was a power dimension needs further consideration, however as Hardwick & Worsley note, when we consider who gets researched the answer is usually “the less powerful” (2011:55). Referring to research subjects Oliver states;

*People who are poor, unemployed, mentally ill, women, black people, disabled people and children are all frequently studied. In comparison research has uncovered little about the lives and activities of psychiatrists, managers, policemen, politicians, policymakers, political terrorists, captains of industry or even researchers themselves.*

*(cited in Hardwick & Worsley 2011:55)*

It may be that social workers should also be added to this list, as they too may be seen as powerful, 'professional experts' in the lives of people with learning disabilities. Oliver suggests "the powerful are rarely studied because they have the resources to protect themselves from scrutiny" (ibid). Whilst this may imply that research is intrusive and problematic, interestingly, outside the research context, the "life story or autobiography [is usually a] preserve that remains largely for the rich and famous" (Atkinson 2010:1). Likewise from a research perspective McAdams & Logan undertook exploratory narrative research into eminent professors via 'life stories' (Holstein & Gubrium 2012:17). However, the life stories of others less prominent are important too, particularly when these can highlight the social structures and emanating inequalities present in society. The voices of the less powerful are rarely given an opportunity to be seen or heard. Where people with learning disabilities have been afforded the opportunity to tell their story it is clear that they too have a richness and diversity of experience, complex histories and a wealth of knowledge relating to life (Deacon 1974, Hunt 1967, Barron 1977, Cooper 1997, Able 2004; see also Atkinson & Williams 1990).

Hardwick & Worsley note that "little research in social work is led by service users or executed jointly with them" (2011:54) stating that academics "tend not to value service user inputs highly enough" (ibid). This thesis however is, as the above authors would like, an attempt to shift that balance in favour of the service users' voice. By adopting a feminist research perspective, I have sought to "promote a participatory model ...where the relationship between researcher and the researched is non-hierarchical, non-authoritarian, non-exploitative and non-manipulative" (Wambui 2013:2). Therefore rather than this research taking an approach creating an unequal relationship, that may occur from a traditional research position, this approach places far greater attention on the individual and the personal relationship with an "emphasis on the daily lives of people their thoughts and their feelings" (Hardwick & Worsley 2011:57). As Wambui highlights, a feminist perspective intends "to bring to the

surface voices that are often excluded from knowledge production and policy making, and critically reflect upon how it can all be done better” (2013:5).

Whilst some have attempted to draw specific parameters around what constitutes ‘narrative’ research (Holstein & Gubrium 2012) Chase aptly details “a wide array of forms and sites of narrativity and narrative analysis” stating “stories have captivated researchers who aim to discover a complex shape of individual experience and social worlds” (Holstein & Gubrium 2012:2). Since the advent of the social sciences, narratives “have been an important source of research material” (ibid) and narrative inquiry remains primarily focused on individual personal stories. Josselson adds that “mercifully [there is] no dogma or orthodoxy yet about how to conduct narrative research, [t]he aim is to elicit stories around a theme in as unobtrusive manner possible” (cited in Wertz et al 2011:2, 6).

Chase (2005) and Riessman (2008) note giving voice to marginalised groups has been an effective tool in their liberation. For people with learning disabilities this is of particular importance. Chase describes narrative research as “an interest in biographical particulars as narrated by the one who lives them” (2008:58). Atkinson suggests it enables us to trace an otherwise hidden history; it allows us to treat people as expert witnesses; it facilitates the representation of people with learning disabilities as fully rounded human beings and moreover it is the beginning of the resistance movement that encourages historical awareness and reflexivity (Grant et al 2010). By its very nature, narrative and life story research allows for the doors to be metaphorically opened and for those inside to give their account of their real-life experiences of what it has been like to live within or on the fringes or margins of society.

### Ethical Research

Research in this vein as Lee describes “eliminates the darker corners of society” (1993:2) and as such may be considered within the remit of sensitive research. Research that is considered sensitive, notably that undertaken with

vulnerable individuals, needs to have an acute awareness of ethical responsibility; but McCarthy notes there is also the danger that managing the ethical considerations may equate with excluding individuals who are defined as vulnerable (McCarthy 1999). The definition of 'vulnerable' itself reveals a differential in power which is at play in research considerations, but it is important to recognise that whilst protecting individuals is of paramount importance, protection should not of itself equate to nonparticipation, as everyone has a right to have their lived experience heard and understood (Hardwick & Worsley 2011). It is useful to be mindful therefore that "there is a danger that the particular challenges of managing ethical issues surrounding research with people with learning disabilities will deter people from engaging in such activity" (McCarthy cited in Hardwick & Worsley 2011: 34) resulting in the further marginalisation and disempowerment of the group which is already disadvantaged, anonymous, voiceless and unheard.

In utilising the narrative approach from a feminist perspective I have set out to give voice to some of the most marginalised and oppressed individuals within society, to hear their take on their life experiences and to translate the learning from this into positive action for the future. As Hardwick & Worsley state 'social work research is usually driven by some issue or practical problem that someone wants to solve or understand, it is purposeful in some way, seeking a particular end, and will make a difference to individuals, groups or organisations' (2011:11). Stenhouse (1983) too suggests, the aim of research is the "systematic process of enquiry made public" (Mc Niff & Whitehead 2009:69) and by extension improve social work practice. Like Pearson my desire is to "engage in research which explores and directly informs practice" (Mc Niff & Whitehead 2009:173) and as a result enable practitioners to understand how doxic assumptions lead to oppression. The focus therefore is to "help to deconstruct the authoritarian voices that speak for or on behalf of others" (ibid).



## CHAPTER 7

### Engagement and Method Used with the Research Group

#### Research Group

The collection of data for this research was made possible by the cooperation of the members of a learning disability self-advocacy group called Be Heard (BH) in Berkshire. This group have throughout given their unreserved support in the completion of this project. From the outset of this research the aim was to hear the voices of those who are often least heard and to ensure their views and experiences of life were centre stage to the writing. Whilst these accounts are not 'full accounts' of a life story or autobiography, they do give a distinct flavour of the lived experiences of the research group.

As McCarthy states "if we want to get the most accurate picture and avoid the filtering out that takes place, there is a strong case for more research asking people with learning disabilities themselves what their experiences have been." (1999:72). In keeping with this emancipatory style informed by various philosophical perspectives, which are discussed in chapter 6, it was imperative for me to ensure that the process was liberating rather than the study being, as Lee suggests, a "study down rather than up" (1993:8). As stated, enquiry was taken from a feminist perspective, characterised by a methodological "emphasis on establishing [a] non hierarchical form of relationship between [the] researcher and researched" (Lee 1993:15).

The link with the group was originally made in 2007 during the development of a social work degree for a university in the Thames Valley region. The group came forward following an advert being placed in the local newspaper for local service user groups to participate with the degree working party. The group, supported by their community development worker, contributed significantly and in depth to the programme's formation. They also provided a range of information as service users to the developing degree and members

of the group subsequently were involved and participated in the degree validation process with the then regulatory body, the General Social Care Council (GSCC). It was noted by the GSCC at the validation event that involvement with such a “hard to reach” group was something to be commended (TVU validation event June 2007). Strangely this term itself is interesting as there is a lack of clarity about what exactly is meant by ‘hard to reach’ groups (Brackertz 2007). The problem with using the term ‘hard to reach’ is that [it] implies a homogeneity within distinct groups, which does not necessarily exist. Thereby ‘it defines the problem as one within the group itself, not within your approach to them’ (Smith 2006:8).

This description of the group as “hard to reach,” which at a basic level I took to mean difficult to engage with, was at odds with my own experience, as members of BH self-advocacy group had also actively supported curriculum development and had been instrumental in devising the assessment tool for a module entitled Preparation for Practice. Overall, members had given significant service user input and subsequently were involved in the on-going interviewing and selection of potential social work candidates on selection days. The notion of BH being a “hard to reach” group seemed a rather strange perception of the situation, at least to someone new to academia and the validation process. Yet as Brackertz notes “Many organisations, but councils in particular, identify hard to reach populations using demographic definitions [such as] young people, rural people, **people with disabilities**, [and] ethnic groups, but it is important to acknowledge that attitudinal aspects are a contributing factor” (2009:8). This research is particularly interested in attitudinal aspects and importantly where they emanate from.

In my role as course leader for the social work degree I was actively involved with the BH group in the early stages of the developing programme. Through my developing and ongoing relationship with the group and also through informally hearing the life events and stories of individual members, it became apparent to me that these narratives needed to be shared with a wider audience, as their life experiences were amazingly diverse. As individual members had talked about their lives I realised their issues resonated with

other concerns I had noted in previous social work employment, particularly in regard to the nature of oppression and discrimination, which obstinately permeates society and social work practice. At the time I was completing an MBA but was considering undertaking further studies towards a Doctorate and these informal conversations were highlighting various concerns that I felt needed further explanation. On successful completion of the MBA in 2008 I asked members of the group if they would be interested in contributing to some future research about discrimination and oppression. All of the individuals who were approached stated they would be willing to participate but that they would need more information about it before committing themselves. In early 2009 informal discussions with group members took place about the focus I wished to look at within the research. This had arisen as a group member had recently given birth and the child had been removed immediately without in the groups view, the member “being given a chance”.

The process for developing the project required a detailed submission to the relevant research and ethics committee of the University of Sussex, which was subsequently approved (ref 1112/03/05). The ethics committee had however flagged up the possibility that an easy read version of the participant information sheet would be beneficial. To ensure this was not problematic two additional actions were then undertaken. I attended a BH group meeting with the BH group and staff members to decide whether a separate easy read version of the participant information sheet was required for the members of BH; and also I undertook training in the use of “Talking Mats” a low tech tool for communication with individuals with learning disabilities or other communication issues (Murphy 2013). The “Talking Mats” method utilises similar aspects of communication to those used at the BH meetings. A paper card with a question mark on it is held up if there is something that is not understood, or an unhappy symbol is used if the conversation needs to stop. Whilst “Talking Mats” can be more in depth than just these 2 issues, the techniques of this low-tech system were already familiar to all of the potential participants. Following discussions with the BH group and the sharing of the information sheet, members agreed they understood what the research was

about, noted it could be supplemented with Talking Mats if necessary so no requirement for a separate easy read version was required.

At the commencement of this research the self-advocacy group BH was funded by a local authority in Berkshire, this had been part of the drive for self-advocacy, which the Valuing People White Paper (Dept of Health 2001) had promoted. BH was part of a wider organisation of supported self-advocacy services (United Voices) and this particular group met on a weekly basis in the town centre, which was extremely convenient for all members in terms of easy access. The group also had use of another easily accessible drop-in facility in the town. Moreover the wider service group (United Voices) also utilised a former day centre that was operated as a café, staffed by members, which contributed to the group's income. Individual group members often accessed the various services across the area. They would frequently drop-in to socialise, for a drink or just to chat with other members and support staff. The development worker and trustees of the self-advocacy service were extremely supportive of the members, who clearly appreciated the services on offer and the safe, friendly meeting places that were available to them during the day.

I had attended BH group meetings on various occasions for a number of events prior to undertaking the research. However in preparation for the proposed research I was formally invited by members of the group to one of their Monday afternoon business meetings on three separate occasions to be part of the group meeting, to explain on one occasion the purpose of the research, to clarify the participant information sheet, and finally to arrange individual interviews and meeting dates with 10 of the members who had agreed to be interviewed. Having attended the three meetings and in collaboration with the support staff, individual dates and contacts were arranged, with the participants. The support staff had also agreed where required to accompany or give lifts to the individual members who wished to be involved. At the outset the meetings were scheduled to take place in the drop in centre, but as the participants were delayed by transport difficulties the

first scheduled meeting did not go ahead. Further dates and times were rearranged.

However, just as the interviews were about to commence the group were informed that the funding for the current provision was to cease and that the local authority would be tendering for a replacement service provider. United Voices the current organisation delivering the contract were advised they would be prohibited from the tendering process as they were too small an organisation to meet the new tendering requirements. The group then invited me in an advisory capacity to attend a further group meeting which was to focus on the possible outcomes for the group with a change to the contract funding and provider. This was linked to me being willing to offer support to the organisation where I could, as I had formerly been a Director/Trustee of one of the possible tendering organisations, and was familiar with the requirements of the TUPE (Transfer of Undertakings Protection of Employment Regulations 2006). Understandably anxieties were extremely high for the group members and also for staff as their future existence as a group was in jeopardy and they knew they would not be able to survive in their present format.

Various members of the group, particularly those on the Learning Disability Partnership Board had requested and had been granted an audience with the local authority and leaders of the Council, indicating their strong wish for the present contract to remain. However, despite their protests about changes to the service provider the tender process went ahead, excluding the existing contract holders and the established BH group of United Voices lost its funding to another national advocacy provider.

The tender was awarded to a larger non-local provider and resulted in significant changes for the members of BH and the support staff. For several months the group ceased and the former established BH group was dismantled, the meeting place and drop in centre closed and all staff were transferred to other posts within the new organisation or left. No former BH staff continued working with the group, although several of the former trustees

remained in touch with members and continued to support them with transport and other issues. A clear sense of bereavement was felt as the support staff and members attempted to remain in contact with me. It was apparent that many members of the group were distressed by this decision and the proposed individual research interviews were subsequently delayed for several months, as the group were effectively no longer in existence and trying to make contact proved extremely difficult.

Fortunately for the purpose of the research, a former member/trustee of BH re-established contact with the university and me, as they were aware that individual members of the group were still keen to remain involved with the university degree programme and also to be part of the research project. Through this contact I was able to obtain individual contact details for some of the former group members who had expressed a keen interest to remain involved with the research. Consequently arrangements were made for these interviews to take place in a venue that members were familiar with and could easily access. At this point I was able to interview three of the former BH group members. The venue where we met was another voluntary organisation's premises in the locality which all members were familiar with, and staff here also knew the members personally as it had been often used previously by the BH Group.

Whilst these interviews were being undertaken the new advocacy service provider was making arrangements for the re-establishment of the BH group, as they had been aware that attending the university as 'service users' had generated some income for the group. As they were keen to continue with the Service User involvement with the university, the project coordinator advised that the group would be reconvening shortly and the former BH members would be having further Monday afternoon sessions. Some 4 months later the weekly meetings for a re constituted group commenced at another venue on the outskirts of the town. Whilst the previous meeting venue was central to the town centre and easily accessible by public transport, some BH members still required support to attend the meetings, support staff of the former BH group had made arrangements to assist the members as appropriate. However, with



the new providers this level of support was no longer available and as a result several former members of BH did not re-join the group.

As stated during this intervening period three of the original BH group members were interviewed at the local voluntary organisations premises. One of these participants had requested and was accompanied by the former staff member of BH, but both other members attended their interviews independently. Once the new service provider was more established and became familiar with the workings of the former BH group activities, members of BH returned to the university as service users to be involved with the selection process, and I was granted fortuitously an opportunity to re engage with BH members who I had lost contact with. In agreement with the re assembled group members and with the new staff at the organisation I was again invited to the group to ascertain if any of the members were still willing to participate in the research, which to my appreciation they were. Following on from this I was then able to undertake a further number of interviews with members from the original BH group at the new meeting place and these took place in 2013/14.

Not least because of the lack of accessibility to the new venue but also because of expressed “bad feelings” towards the new provider the number of individuals who could be engaged with had reduced. Therefore from the original 10 members who had agreed at the outset to be participants in the research, the actual number of people interviewed was reduced to 7. Whilst I recognise only a small number of individuals gave accounts of their experiences what they shared was rich and informative and is unfortunately echoed elsewhere (Quarmby 2013).

#### Social Work involvement

Alongside interviewing service users with learning disabilities the original plan of the research was to interview a small number of social workers with experience of working with people with learning disabilities. This was initially arranged with a local authority partner of the university located in a different area to the group. This had been considered because it was felt by my

supervisor that a professional view would be beneficial. However as my focus has always been the service user view, it was interesting to note how extremely difficult it was to access social workers for interviewing purposes. Whilst accessing service users was logistically problematic, reaching more local social workers has proven to be far more difficult. Subsequently interviewing the social workers that had initially agreed to participate had to be abandoned; as Mc Niff and Whitehead note sometimes “problems are irresolvable and sometimes you have to walk away” (2009:145). Somewhat ironically, it transpired social workers for legitimate reasons were the ‘hard to reach’ group.

The lack of engagement with social workers that had initially agreed, arose because of significant changes in their work place, austerity measures and budget cuts had led to downsizing of the workforce, two were facing redundancy and a further worker had opted to leave the Borough. This fact made the social worker participants physically hard to reach. Whether those who had agreed to participate were in some way different from those who remained in the workplace is an unknown quantity. Whilst it has been possible to gather data from a range of people supporting individuals with learning disabilities; the inclusion of social workers in more formalised interviews proved to be a step too far within the current constraints. However it is not to be assumed from the change of plan that other voices of professionals, potential social workers, social workers and others working with people with learning disabilities have not been considered or included in this work.

To this end it should be added that several telephone conversations took place with social workers and support workers, their comments and observations were recorded in note form and through email exchanges. This was also the case for the telephone conversations and emails to 2 organisations that I contacted who offer support to people with learning disabilities. One of these, the Parents with Disability network (PwDN) based in Bristol, offers considerable support to parents with learning disabilities and includes a Social worker who also works in the service. In conversation with the coordinator the extent to which the current funding cuts were affecting the

service and the challenges faced in maintaining support to service users were highlighted. This mirrored the local experience and the comments social workers had been making and also how this was placing significant demands on their time. Moreover the coordinator from PwDN reiterated the findings reported in a range of sources, that disabled parents faced a real struggle in being allowed to keep their own children. (Quarmby 2013. Grant et al 2010, BBC 3 2015).

The information sent by email or discussed by phone, contributed to the material presented here, plus it guided me to further reading material and statistics. In essence the discussions and comments focused on the dilemma experienced by social workers, where they are involved with parents with learning disabilities and child protection. It is evident that the focus of ensuring the safety of a child, takes precedence over all other considerations. From the comments shared it was acknowledged there is a limited understanding of the wider historical context of the disabled experience, child rearing and also of the different and raised expectations of parents who are tested for parenting skills which non-disabled people are automatically assumed to have.

### Research Focus

As previously mentioned, service users who had witnessed the grief of one of their members who had lost her child at birth in child protection proceedings had been involved in the shaping and focus of the research. The experiences of group members shared in conversations, resonated with discrimination and oppression in all aspects of their lives, uncovering the rationale for this was a shared aim for us all. This is in keeping with Davies' (2005) view of involving service users in the design and management of research. The focus to gain an understanding of the causes of oppression and to involve service users in the way the data was collected and used took place in the early meetings, as did determining whether the participant information sheet needed an additional easy read version. Key considerations in the research were "the dignity, rights, safety and well-being of the participants" (Davies 2005:18).

These were all issues that were discussed in depth at the BH meetings at the outset, and hence additional support was provided where it was requested.

### Research Process

At the commencement of each of the interviews with the individual members of BH, each participant was welcomed and thanked for being involved; each participant was given the participant information sheet and this was briefly explained, as was the issue of confidentiality. Interestingly each member interviewed recalled having all of this information discussed at the BH meetings previously, and stated they were aware of the purpose of their involvement. This was also true of those interviewed at a much later date. Participants were asked if they were still willing to be interviewed and also if they would be happy to sign the consent sheet. Participants were reminded that they did not have to take part if they did not wish to and that if they changed their mind at any point this would be respected. All participants indicated a desire to continue and all expressed the view that they would like the BH group to be acknowledged even if their individual contributions would not be identifiable. To ensure that no BH members would be upset or distressed by the process, BH members were advised I would be following the format of intervention that was used at the BH meetings, notably that one would raise a pictorial card to stop or pause the meeting, if they wished, for example to ask a question, or because it was upsetting, or to have the question repeated. To this end I utilised the "Talking Mat" (Murphy et al 2013) system, "Talking Mats" cards are similar to the card system at the BH meetings and were also available during interviews if required. I then asked if the interview could be recorded, and if I could make some supplementary written notes. All participants agreed to these requests. To explore the life experiences of the individuals I spoke with I commenced each interview by asking the participants if they could tell me, "In your life what has been the good things, or not so good things, and what would you like to be the same and what would you like to be different?"

All of the participants then began to recall with considerable ease various aspects of their lives, which they considered to be good or not so good.

Whilst no specific questions were set for the research interviews as the “life story” was what was being sought, during the interviews some additional questions were asked either for clarification of issues raised or in response to comments regarding relationships and aspirations for the future. At the conclusion of each interview each participant was asked if they were happy with what they had shared with me and would they be willing for me to use any of their responses in the research paper. All participants agreed to the use of their material. I also added that the information shared would be confidential and they would not have their individual identities disclosed. However the members of the group reiterated their wish that the BH group had supported this research and would like the group to be acknowledged and recognised for their contribution to the final report.

### Research Participants

The interviews with the seven participant individuals ranged in time from approximately 20 minutes to one hour and 20 minutes, with the average being about 40 minutes per interview. The ages of the 7 people interviewed ranged from mid 20s to early 70s with the majority of interviewees being in their early 40s. Five of the participants in the research were male and 2 were female. Of the 7 interviewees only one had any children. None were married or co-habiting, although 3 were involved in long-term relationships. All participants were white British, and the group has no members who now currently attend from an ethnic minority background. All of the interviews took place in a quiet interview room either at BH premises or at a venue familiar to the participants. With the exception of Sharon who had requested the attendance of a support worker all of the interviews were on a 1 to 1 basis.

The data for this research is predominantly based on the life experiences of seven individuals with “learning disabilities” one of whom also has “autism.” The individuals have all been members of a self -advocacy group in their home localities. However within this context it has to be remembered that learning disabilities and / or autism are not unproblematic definitions (Grant et al 2010:3) as they are also influenced by social constructions. The members

of the BH group who were interviewed had all been involved with the self advocacy service for at least five years prior to the research commencing. I would suggest that involvement in this supportive group could well have been a contributory factor in the confidence and zeal with which participants engaged throughout the whole process. As Atkinson suggests, being able to tell the story of individual life experiences is “particularly important for people with learning disabilities because often they have been silent or silenced” (Atkinson 2010:7). However as Mathews and Crawford rightly note they offer “unique expertise and a significant contribution” (2011:27) to the social care debate.

The development of the relationship with BH members over recent years with the degree programme had created a trusting and positive rapport between BH members and myself. This is in contrast to the “deep seated distrust of social services” (SCIE 2005) representatives that has been expressed by service users in other findings. The approach taken to the research from the outset was notably that “learning is based on the principle that the source of understanding is [in] the lived experience of [the] individuals” who had lived it (Smith, cited in Mee 2012: 15). Although much has been talked about the valuing of people with learning disabilities (Dept of Health 2001 & 2009) an issue that is explored in chapter 4, Mee notes some research approaches do not demonstrate a sense of “value” of the contribution people with learning disabilities make to research. In citing evidence, particularly in regard to evidence-based practice Mee suggests there is a “league table” which places lived experience at the lowest level of evidence. Mee goes as far as to say, “it would seem to exclude first-hand accounts from those who are not respected and this presumably includes accounts from people with a learning disability” (Mee 2012:16).

However from the empirical stance taken, I have followed Pearson (2008), who states

*I wish to engage in research, which explores and directly informs practice. [To] view my role as a professional educator to facilitate opportunities for people to use their*



*own voices and to express their experiences..... And help to deconstruct authoritarian voices that speak for or on behalf of others*

*(Pearson, cited in Mc Niff & Whitehead 2009:173)*

### Research Analysis

In hearing the voices of those less heard, as stated I engaged in individual interviews that were both digitally recorded and supplemented by additional notes. An initial attempt to transcribe the recordings verbatim was abandoned, as I was unable to decipher clearly what had been said. During the interviews I felt I had understood the flow of the conversation, much easier, perhaps because of facial expressions, body gestures and being 'in tune' with the participant, but in attempting transcription this clarity was lost. Therefore I decided to listen to each recording x 3 to establish if I could retrace my previous clarity to what I had been told, on re hearing the voices and recalling the situation mentally, the clarity of the accounts shared was far clearer. By re-listening to the recorded voices, I was able to regain the "tuned in" experience I had felt and recall the individual speech, the tone and inclination of the speakers and the general sense of the situation that had prevailed at the time of the interview. As stated I re-listened to the recordings x 3 for each participant, and made further detailed notes. By utilising this method and by cross-referencing to the earlier written notes, I was able to clarify more precisely what each participant had told me. Nonetheless by the time I had reheard the voice recordings I also surprised myself as to how I had so poorly misunderstood a few of the comments in the first instance. For instance I had originally written in the notes the participant as saying "Alice Higgins" when in fact they had said "a lot of chickens". This aspect of listening to the audio recordings helped me to appreciate that spending more time listening to individuals who at first seemed unclear would prove to be extremely beneficial in my future work. In addition I was able to appreciate and carefully note the subtle change in tone of voice during the recollection of sad or unpleasant experiences and also the proactive changes in direction of the conversation when the topic was something the participants did not wish to explore. For example one participant mentioned how extremely violent the residential school they had attended had been, then immediately and what felt

imperceptibly at the time, moved on to discussing the primary school they had been at many years before. Although I had had some sense of participants leading the direction of the interviews during the original interview meetings the extent to which this took place became far more apparent on the re-hearing of the discussions. In essence by utilising this method I was able to gain a fuller view of the participants' experiences and of the benefits of re-visiting and listening to the spoken word.

The most striking aspect of listening to the recordings was the manner in which the life experiences and stories of people with learning disabilities reflects "the ordinary, the everyday and the mundane" (Atkinson 2010:7). Yet this is against a backdrop of oppression, discrimination and limited life opportunities. As Mc Climens and Richardson note the stories of people with learning disabilities are "largely reflective [of] the resilience of the human spirit, revealing that people with learning disabilities, in contrast to eugenic assumptions, develop throughout their life span, adapting to changing circumstances much like the rest of people in society" (Grant et al 2010:28).

## CHAPTER 8

### The Life Stories

*Without coming to terms with painful history, the present remains poisoned.*

*(Quarmby 2013:225)*

The Be Heard group members interviewed in this research reside in the unitary authority of Bracknell Forest, one of the six authorities in the County of Berkshire in the South of England. The authority has a population of just over 113,000 with an even split of 50% males and 50% females, it is predominately white British, 84.9%, and a 15.1% BME population that is slowly increasing (Bracknell Forest Council 2013). It is a generally affluent area with a higher than average representation of professionals and managers residing in the locality. Considerably higher than the national average is the perception that in regards to health, most living in the area consider themselves to be in 'very good' or 'good' health (Bracknell Forest Census data 2011), with 12.3% of the population reporting a long term health condition or disability (ibid). However this information does not give a detailed account of incidence of learning disability or autism within the area. Statistics in regards to prevalence of learning disability is not available in the census data, and neither does the local authority hold a Learning Disability register, however I was advised by the Adult Services Learning Disability team that 380 individuals are known to their services.

This thesis will consider the experiences of just seven of the individuals in this geographical area, some of whom may not be known to the services mentioned above. The seven individuals from the Be Heard group have shared with me aspects of their own life stories, and whilst I acknowledge these experiences may not be representative of the 380, I will later be linking their stories to the history and theories explored elsewhere in this thesis. However as Aiden & Mc Carthy rightly note "negative attitudes toward disabled people are widespread" (2014:7), so it is interesting to see how such

negativity impacts on the lives of the seven participants interviewed. The following section of the thesis details aspects of the stories told. The individual identity of each participant has been safeguarded by the use of pseudonyms.

### '24 Hour Care'

Carol is a woman in her early forties, who is humorous and friendly. Our interview commenced with her saying to me with genuine concern in her voice if I felt well? I said I felt fine, but I asked her why she was asking, she replied to me "because you are covered in spots"; I was wearing a polka dot dress at the time. As I had asked Carol to tell me about the good things and not so good things in her life she commenced her response by stating that she had experienced over 20 years of "full-time 24-hourcare" and that she "did not like it; people telling me what to do constantly... you can't do this, you can't do that, I had no choices". As to why she had been placed in 24-hour care, it seems a social worker had suggested she go. So at the tender age of 16 she was moved to a "learning centre" in Hampshire some distance from her parents in Berkshire, ostensibly to work with horses. Although acknowledging that she had wanted to move away from home, as she was not getting on with her parents, she had not anticipated what was to become a 20 year period of incarceration.

Today Carol lives alone in a one bedroom flat in Berkshire, supported by her care worker 3 times per week and also by her boyfriend and his parents. Carol now gets on well with her parents and often babysits for her nieces and nephew – her sibling's children who are 6, 4, 5 and 3 years old. During the period of "24 hour care" as Carol described her incarceration, she experienced bullying and other abuse which she was unable to discuss with me. Carol explained as result of her experiences whilst in 24-hour care, she has been going regularly to counselling as the people she had lived with had "made me really upset"; they had done "nasty things to me" and it was "not nice". At this point of the interview Carol became quite upset but although she did not want to elaborate further on these events she wanted to continue telling her story. Carol then began to talk about another group member of the self-advocacy group (who I shall refer to as Belinda) who Carol found

supportive at the time of the counselling, as Carol stated Belinda had also had similar experiences. In fact Belinda had conceived a child in unexplained circumstances and her parents had supported her to keep the child. Belinda was now one of her best friends. Whilst Carol could not, or chose not to fully explain the nature of the hurt and injury experienced whilst in 24-hour care it is clear from Quarmby (2013) and Newman (2015) that these types of situations are not uncommon in so-called care environments. Macfarlane cited in Quarmby notes that the treatment witnessed was often cruel, inhumane and threatening. Newman (2015) also suggests that human rights are breached on a daily basis in many of the so-called 'care' provisions. Winterbourne View is just one example (Minchin 2012).

Although Carol does have the benefit of living alone in a property with what she describes as a "very helpful landlord", who ensures everything is repaired when it needs doing, she stated that while she liked the support workers she found them bossy. When asked to explain what she meant, Carol told me that her support worker goes shopping with her but tells her that she can only buy the things she really needs. If she buys chocolate the support worker says to her "Do you really need chocolate?" Carol has tried going to the shops alone but the support worker then asks to see the receipt and nags her if she has bought chocolate or anything else she considers Carol doesn't need. On another occasion Carol had purchased a t-shirt and the worker had said to her "Why did you buy that? You don't need it?" Carol then said "sometimes I go to Costa coffee on my own and I buy a coffee and a Belgian tea cake, as I really like them" but my worker "tells me off and says buy things you do need."

In terms of employment Carol has two voluntary positions - one in a local café and one at the local hospital, she also works at Tesco's shelf filling 2 evenings per week. Although Carol states the people she works with at Tesco's are friendly to her, none of them socialise with her outside of work. Despite the constraints imposed by the support workers on her financial freedom, who suggest that what she needs is "cleaning stuff" Carol describes her life as being much better and says "I do not want to go back to having no choices". Finally Carol describes her boyfriend whom she has been with for several

years as her “toy boy” as he is 4 years younger than her. They holiday together and she spends most weekends at his home, and although she would like to marry, her boyfriend just says “one day” but she thinks that will be when she is old. Carol says she doesn’t want children but she “would like a fairy like the ones in Snow White, the ones that come and clean your house for you”.

### “Totally Boring”

I also interviewed Sharon, a woman in her early fifties who had requested she have the support worker from the Advocacy service with her as she was aware her speech was not always that clear and the Advocacy worker understood her well. Sharon also had experienced significant periods of ‘care’ having been removed from her parents as a child. Although Sharon could not recall her age at the time she was taken into care, she explained it was a “very bad” time and she was “very unhappy”. Sharon explained that her brother and 2 sisters had been in care with her. Although their Mother would visit regularly she remembers that when her mother would leave she recalls feeling upset at not being able to go home. Sharon described that the family had lived in a caravan with her parents and siblings, although very overcrowded it was “lots better than the children’s home”. When they eventually returned home, some years later they were moved from the caravan to a house, which she still lives in now with her brother and sisters, although Sharon explained that one of her sisters who had suffered from epilepsy had recently died.

Sharon also recalled that following on from school she was sent on a daily basis to a day centre. She described it as “totally boring” with nothing to do: “Only going for walks”. She remembered when she was at the day centre having a “really bad pain in [her] back,” so she went to the GP who told her she was pregnant. She did not know or could not remember how this situation came about, but she was very pleased that she had given birth to her daughter Megan who was now in her late 20s. Although Sharon gave no indication of how this conception occurred the Equality and Human Rights Commission have noted that more than 70% of women with learning



disabilities are sexually assaulted (EHRC 2009). Whilst many women with learning disabilities have their children removed from their care and have little opportunity for interaction, Sharon remained in contact with Megan as her own parents and siblings took on the care of the baby. As Sharon described to me her experiences of having had a daughter she was visibly thrilled and described it as “one of the best things ever to have happened in my life”. However although Sharon did have her daughter and is able to still see her, I asked Sharon what she had called her baby but Sharon told me that after the baby was born the baby became her mothers and her mother chose the name. Sharon stated she had held the baby once at the hospital and has a photograph of this at home. Sharon recalled that “my Mum’s friend made me a frock” (maternity dress) and “my Mum bought everything, a lovely pram, baby bath and everything that was needed”. Megan, (Sharon’s daughter) now lives in a nearby town and has her own children and visits Sharon often. Although still living at home with her siblings, both parents having died, Sharon attends respite care on a monthly basis, as one of her other siblings also has epilepsy and her main carer (eldest sister) needs to have a break. Sharon described the respite provision she now attends as having been “done up” and “it’s really nice now with its own bathroom in the room”.

Sharon stated that she now has “plenty to do.” Whereas previously “things were really boring” she is now allowed to go out on her own, “I can catch the bus and go where I want”. “I like going to the gym, I like playing table tennis and I like going to Be Heard meetings”. Sharon has been working voluntarily as a cleaner and a dishwasher at a local hospital and also at Tesco’s, but her employment support worker had told her to give up Tesco’s as it was too much for her. Sharon said that her Social Worker now is “really good” she likes him a lot as he has “helped me to get out a lot more”. Sharon described that now “her life is good”.

### “I Love Spain”

Unlike the other members of the self-advocacy group Timothy was a much older man in his early 70s. He too had experienced 24-hour care as he had been sent to a Boarding School from age 5 to 17. Timothy’s parents had kept

in regular contact with him during these years and overall his experience at the Boarding school had been positive, which is unlike the experiences of the other people interviewed. Timothy was even saying he would like to go back. On completion of his education Timothy returned to live with his family and with the help of his parents he had been able to secure a job with a haulage firm as a driver's mate, and later on trained to drive a forklift truck. Timothy's opening comment was that he really missed his parents and that he thought about them every day. He considered he was fortunate because his brothers and sister were still alive and between them they helped him with his shopping, cleaning and sorting out financial matters.

Timothy stated that because he had worked all of his life he had his own money from his pension and that "he didn't want to be treated like a criminal" because that is how he felt when he went out to the pub. He said, "people get nasty" as they don't want him there. As Quarmby has highlighted in regards to people with disabilities, whilst politicians suggest it is about a lack of respect or a lack of community, in reality "It's about the community not wanting disabled people to live in it" (2013:157). Timothy had lived with his parents in Ascot, from age 17. His father died in 1966 aged 56, but his mother lived until she was 87 and died in 1999. Since then he had moved to a flat in the local town and had now lived there alone for 16 years. Timothy told me he is reassured each night, as he states his Mum talks to him and says "Timothy look after yourself" and "I do look after myself and I am doing alright". Timothy says that when he is out people are always telling him "you're spending too much money". Timothy stated what "business is it of theirs? It's my money." He also added that people say to him "you've got a lot of money" but "I worked for 42 years for a firm in Ascot" so his financial situation is understandable as alongside his state pension he also has a company one.

It is clear from Timothy's description that his good financial position is not what is expected for someone with a learning disability. The attitudes and expectations of appropriate lifestyles and behaviours people perceive for him come to the fore when he explained that people suggest to him that he should go on holiday to Butlin's, "because that's where people like you go" rather

than to Spain which he has done 59 times. Timothy said, "I like going to Spain, I love it and I meet different people and they are friendly". Timothy then added that people say to him "why are you going to Spain all the time?" but he replies, "It's my money I'll do what I like with it". Timothy then stated "where I go is my decision I'll go where I want to go" "I can stand up for myself, and I can look after myself".

I would suggest it is inconceivable to imagine that people would consider advising anyone without a learning disability what they should do and where they should go for their holiday, and it is even less likely that they would be complaining that you have a lot of money. However this is the experience for Timothy whenever he goes out to the pub, which he has now curtailed because he "doesn't want to feel like a criminal". Timothy has also just returned from a trip to a family wedding in Australia and stated he is going back there for a month in December. When asked about his own relationships Timothy told me that over the years he had "been friends with a number of ladies," that he would have liked to get married and one day he might, however what worries him is that many of "the ladies seem to be more interested in my money". Timothy states he is happier helping nice people like the members of the Be Heard group so that is what he will be doing now. His contribution, as Timothy informed me, is that he is the representative on the Health group from the local Learning Disability Partnership Board (LDPB).

Although many of Timothy's trips abroad elsewhere have been with family members, Timothy has travelled to Spain many times alone. On many occasions people have suggested and encouraged him to accept that they accompany him at his expense, but he has replied to them "you can come but I have paid my fare you can pay yours". Timothy also added they often respond saying "I've no money" to which he replies, "You can't come then!" Whilst Timothy has been able to resist what can only be described as opportunities to exploit him, other people with learning disabilities have not been so fortunate (see Quarmby 2013).

Spain has been Timothy's choice of holiday place so frequently because he feels that people are nice and friendly towards him there, he does not feel that

he is subject to the same level of abuse that he gets at home, and from which he frequently walks away. Timothy said he likes to “meet nice people and friends to have a chat”; he doesn’t “want to get into trouble with the police” because people are frequently “nasty” with him but “I walk away, my Mum will be proud of me”. As Quarmby notes, disabled people experience this kind of behaviour on a weekly if not daily basis, as she reports, people “with learning disabilities were used to being spat at in the street, pushed around on the buses when schools were out, or called names” (2013:112). As will be apparent this is a common theme in the people interviewed. Moreover people with learning disabilities are often reluctant to raise a complaint, not least because the likelihood of being ‘protected’ imposes even more restrictions on their lifestyles than they already have. On hearing Timothy’s comment, of defending himself I was reminded of the case where a woman with disabilities had said, “I’ll stick up for myself” was then urinated on, kicked violently and covered with shaving cream as she lay dying in the street (Quarmby 2013:135).

Given the extensive amount of travelling Timothy has undertaken, he has only had a major problem on one occasion, when he missed the flight because he went to the gate too late, as he had stopped to buy a cup of tea. Clearly despite being treated quite badly at times by members of the community Timothy has been able, due to his financial independence and family support network, to have a reasonable quality of life only marred by negative attitudes of those who regard people with learning disabilities as problematic. He says “the worst thing that happened to me was when I missed the flight, my brother was very angry with me, as he had to collect me from the airport”.

#### “I Have a Wish List”

Whilst Timothy seems to have coped reasonably well with the socialisation opportunities he has, Karl, a man in his fifties who lives in shared accommodation with other people with disabilities, describes being repeatedly followed whenever he is out walking. He says this “scares” him. He does not know why they follow him but he finds the experience extremely intimidating.

Mencap reported in 1999 that 80% of people in a similar situation to Karl were also scared to go out (Quarmby 2013:147). This is hardly surprising; Mencap found that nine out of ten respondents to a study they had undertaken “said they had been bullied. A quarter had been physically assaulted and 73% taunted in public” (2007).

Karl who originates from Birmingham had also experienced a lengthy period of institutional care. He had been sent to a residential school as a young boy. He did not recall how old he had been when he was sent to the school, only that his mother “couldn’t cope with him”. When asked about being at the school Karl became silent and clearly did not want to talk about his experiences there, other than to say he recalled chasing the cows down the path. However as Petersilias (2001) has found, being a disabled child doubles the likelihood of suffering abuse, moreover Mencap have reported that 80% of children with a learning disability have been bullied in school and 60% have been physically hurt (2007). It would seem that from an urban life in Birmingham, Karl had been placed away from home in a rural area in Berkshire where he subsequently lost all contact with his family. Karl did not know if he had any brothers or sisters nor was he aware of who his father was, but he had been told that his Mum “was in heaven now”. Karl had remained in a residential care home that he described as a place where lots of people lived. Although Karl stated the place changed its name several times during the period he was there, he remained “in care” until approximately 10 years ago when he was moved into a “shared house with 3 others, one is in a wheelchair”. This was the first time in Karl’s life that he had been given his own bedroom, and Karl’s greatest desire is to have “a place of my own”. Although his support workers have told Karl that they will help him to secure a place of his own and he believes his care manager is supporting such a move, he has been advised he will need a 2 bedroomed house in case “he falls out of bed at night”. I asked him if that had ever happened to him previously and he said no, so the rationale for telling him this seems a little bizarre. I asked Karl if he liked where he lived now and with a resigned tone in his voice he said, “It’s ok but I would like to live on my own”. Since an early

age and for over 35 years, Karl has had to live in shared accommodation, and it is something he really does not want to do.

Unlike Timothy, who has worked for all of his adult life and been able to gain his own financial independence, Karl has only worked intermittently and usually on a voluntary basis. Karl described working in a warehouse moving furniture, but stated he would like to work in a Sports centre. He was always looking for work but to date he hadn't been successful. He described that he just had enough money to live, for food and things but he needed to save up for everything else, so he had created a "wish list". When asked what was on his wish list Karl replied, on the top are jogging bottoms, a bike is in the middle and a tablet (I Pad) was at the bottom, but he was hoping that he might get the tablet for his birthday if he gave the support workers the money for it.

Karl advised that he likes to cook, and said "we take it in turns to do the cooking and shopping" and added that he wants to bake a cake for his birthday, which is soon. However it seems the staff have planned that this year they are going out to McDonalds to celebrate. I asked Karl if that would be nice and he said, "No I don't like McDonalds as I only have the salad there, I don't like burgers".

When asked about how he spends his time Karl advised that he plays football at weekends (Saturday) and he attends kick boxing one night a week. He goes to various activities such as job club and drama, and says "I try to keep myself busy, I like it that way". When at home Karl describes how he enjoys doing arts and crafts, drawing and painting, especially owls. Karl added he now has a collection of owl ornaments. Karl stated he would have liked to get married but wouldn't want children, as they are too difficult to look after. He describes his life as better than it was but when asked what he wanted, he said he would like a job to earn some money and a place of his own to live. If he had his own place to live he would dearly love to have a rabbit. Karl concluded the interview by saying the support staff at the shared home had booked a holiday for the residents at Butlin's in Minehead so he would be



there for his birthday. His expression and demeanour did not convey that was something he was particularly looking forward to.

### “Just Walk Away”

Another group member Adam, is a man in his late forties, and likewise experienced a lengthy period of care, he too had been sent to a residential school at an early age. In Adam's case he had been taken to the residential school on his 13th birthday. Prior to going to the residential school Adam had been attending a local school in the area but since his 13th birthday Adam had remained in institutional care until approximately 4 years ago, meaning he has spent at least 30 years or more in an institution. When I asked Adam about his time at school he just said it “was a bad thing, it was a bad thing”. The expression on his face was one of great sadness and he asked for a drink of water. I did not ask any further questions about his school, Adam then started to talk about his time when he was in a care home and he was tasked with looking after what I had interpreted as Alice Higgins, Adam became extremely frustrated with me when he repeated this several times and I realised he had been saying “a lot of chickens”. It is the case that people with disabilities are often marginalised and treated as “hard to reach” (Lambat & Lambat 2011) because of communication difficulties, but patience and calmness can help overcome these issues. In the main Adam had enjoyed a caring role of feeding and watering the chickens and collecting the eggs, the exception to this was hearing strange noises at night, he had gone to check the chickens only to be confronted with a big rat, at the sight of this Adam said he screamed and was put off looking after the chickens. Having spent many years in residential care Adam eventually moved into a shared house provision approximately 4 years ago. He believes the main reason for the move was because he could “no longer manage the stairs in the hostel”. He recalled suffering a great deal of pain in his knee and had been hospitalised as a result. Adam described being moved from various care provisions over the years, and is now very happy to be living in a shared house, which he moved to in 2012. Adam took great pleasure in describing all the rooms in the property and stating that he now has his own bedroom and his girlfriend Jocelyn who also lives there, has her own bedroom too.

Although both Adam and Jocelyn moved from the same care home and have been in a relationship for about 5 years, and would like to get married, Adam has been told they cannot share a room. I asked why they had been told this Adam replied that the care workers who support them had told them it would affect their benefits. They also said to him "it's not allowed, they would tell my family if I did that", he said he didn't want to cause trouble for them (his family). When asked if he eventually married would he like to have children Adam stated, "never that would be too big a step" but he added he did not agree with abortion as "that is wrong". Although Adam and Jocelyn regard themselves as a couple, when it comes to holidays the support staff arrange for separate holidays for Adam and Jocelyn to different places at different times. Adam is not happy about this. Whilst Adam prefers his current living situation to anything that has gone before, primarily as he feels he has much more freedom, he can go out when he wants, he can walk to town and catch the bus to different places, unfortunately he has also experienced abuse in the street. Although he said he had not experienced 'hate crime' in the way the others at Be Heard have, (the self advocacy group have made a DVD on dealing with 'hate crime") he says this is because "I walk away, if you don't walk away it makes things worse. Linking the importance of walking away from bad situations, Adam spoke of the outcome regarding the new contract holders Just Advocacy who in his view had treated former support workers of Be Heard very badly. In conveying this Adam stated that whilst he likes the new person from the advocacy service he felt Just Advocacy had done wrong, explaining they had been very unkind to Marcia (former support worker) and they had broken the law, but Marcia had also to walk away.

Adam also advised me that whilst he liked living at his current address, recently the support staff had taken his bankcard from him. When I asked why this had happened Adam told me that he "had wasted his money", I asked him to explain what he meant by this, he said a couple of months ago he had gone out and bought some magazines, so I asked what magazines he had bought. Adam explained that he really liked Liverpool Football Club and he was wearing a Liverpool top at the time. It transpired that he had purchased 3

football magazines in one week. The support staff had told him that was totally unnecessary, in future they would look after his bankcard to prevent him from wasting any more of his money. Adam had accepted this. In concluding his interview Adam finished by saying, "sometimes people do pick on me and sometimes they don't but it makes me feel proud that I walk away".

#### "Student of the Month"

The youngest person to be interviewed, Thomas, was the only member of the group who had not been in residential care. However unlike the other group members Thomas's learning disability had arisen out of a brain injury following a road traffic accident in his childhood. Prior to the accident, Thomas, a male of 24, had attended a mainstream school although he had little recollection of it. Following the accident he had been transferred to a "special school" where he recalls being called upsetting names. Although he did not experience residential care, Thomas described the journey to and from the special school as particularly tiring and wearing. He would be picked up in the morning at 7am and the bus would then collect a number of other pupils so the journey into school was often 2 hours or more every morning. Likewise the return journey home involved a further 2 hours on the bus and on occasions he would not get back home until 6:30pm or 6:45pm if the traffic was bad. Thomas explained he remained at this school until he was 18, undertaking the lengthy journey every Monday to Friday. Although not recalling particularly positive experiences of his schooling, Thomas stated he had obtained quite a few certificates, and recalls being "student of the month not quite every month but a few times".

Throughout his life Thomas has remained living with his parents and siblings but states he would like to have his own place. His elder brother who is married and lives elsewhere has 3 children. When asked if he would like to marry or have children Thomas stated "I'm not the marrying kind". Although Thomas has a girlfriend who attends the same day centre, she would like to marry, however Thomas says he is "not ready for that yet". Thomas also said he can no longer have children as after his accident he agreed to be operated on (sterilised).

Thomas has never worked, other than as a service user at UWL where he assists in selection days and role-plays with students on the Social Work degree. Most weekday mornings are spent at a local Day Centre where he does what he described as “art stuff, painting, ceramics and pottery”. Thomas also has some mobility issues as a result of the accident but he uses the Dial a Ride service if he wants to go out and his parents will take him to and fro if this service is unavailable. However due to the timings and availability of the Dial a Ride Service it seems that Thomas’s mother often needs to collect him from the venues he attends.

Although Thomas likes going to the local pub and to the town for shopping he has encountered varying levels of abuse. Thomas described this as “people staring at you or making fun of you”. He also added that people often make him feel uncomfortable, whether it is in the pub or in the shops, but that often in the shops they “just completely ignore you”.

#### “I’m the problem because of my disability”

Similar to Timothy whose parents had found him employment on leaving residential school, Jason had also worked for a few years in employment obtained through family connections. However Jason has also been in a number of residential care provisions. Jason, a male in his early forties, has had considerable experience of the care system, social workers, and mental health services. Jason explained his mother abandoned him at a children’s home when he was aged 3. Hollins & Sinason (2000) have noted parents who experience the birth of a disabled child often grieve for the ‘perfect child’ who was anticipated and research has shown this can lead to insecure attachment and rejection. Jason has been told “what happened was my mum took me to a children’s home and walked out, and only told staff my name”. “Apparently didn’t say goodbye to me or anything, she just walked out of the children’s home and staff were left with a child they knew nothing about”.

One of the most vocal members of the group that I interviewed, Jason commenced by stating that he was not given a diagnosis of Aspergers until he

was 27, although he also added he was unable to speak until the age of 12. Today Jason is a very articulate man and is able to discuss his life experiences and challenges in depth and he explained that he was first placed with his foster parents when he was 4 years old. He says the delays to his speech created problems in the family. Jason blamed himself for this, stating "I caused quite a bit of the problem because of my disability". Because of the attitudes expressed towards people with disabilities, their self-esteem is often extremely low and as Quarmby rightly asserts some people, "especially those with learning difficulties, internalise that prejudice" (2013:220) as is the case here. Moreover Jason attributes his abandonment by his mother to the fact he looks identical to his father who walked out on her after his birth. However it is often around 18 months to 3 years old that Aspergers becomes more apparent in children who appear to be physically very well, Howlin & Asgharian have found "Parents of children with a diagnosis of autism were generally aware of problems in their child's development by 18 months of age; in the Asperger group concerns emerged later, at around 30 months of age" (1999). From information shared with him, Jason described that his father is a "con man who travels the country getting money out of people and every so often gets caught". From what he has been told "he is in and out of jail". As a child he believes Social Services placed a ban on his father knowing where he lived.

It seems Jason's foster family were chosen as his carers as they were members of the 7<sup>th</sup> Day Adventist church, as his own mother had been. Whilst this seems to have been positive, Jason stated that he has "blanked out everything until age 8" and presumes this is his own defence mechanism. From what he recalls the Social Workers that he was involved with would insist that as a child his free time at weekends needed to be engaged in socialising activities to enable him to become more communicative, despite this going against the family's religious beliefs.

Whilst Jason has described that his foster parents struggled to understand him, he recalls that they were relieved he was not getting into any trouble, but this all changed when he was told by his foster parents that they were getting



paid to have him. He described how “they weren’t wanting me because of me, they just wanted the money”. At the time Jason was also being bullied at school and at age 12 he describes having a psychotic episode and being admitted to an adolescent unit where he remained for over a year. Due to having been in the adolescent unit, finding a suitable school for Jason proved to be extremely difficult, and eventually he was placed in a school near Exeter in Devon, which is a considerable distance from Berkshire, a journey that either by car or public transport can be in excess of 3 hours. Jason described the school as being “violent, very violent but you would expect it with the background of the boys who were there”. On completing this statement Jason then went on immediately to say although no one had expected him to achieve he had obtained 2 O levels whilst at this school and obtained a further O level when he later attended College. So whilst Jason noted the violence at the school he felt it had helped him. In his words, “they knew how to handle people with problems”.

Jason remained in the school residential setting (52 weeks per year) until he was 18 and states his foster parents never visited during this time, although he states he kept in touch with them by letter, because he was forced to. At 18 he returned to the foster carers for six months and was then given his own tenancy in the area. At this time his Social Worker had arranged for him to attend a Youth Training Scheme (YTS) programme, which lasted for 1 year, on completion of this he was still unable to find any work; to ensure he still had some income the Social Worker arranged a further years extension of the YTS for Jason. During this time Jason was utilised to decorate various properties, although he states he wasn’t particularly good at it. At the end of 2 years on the YTS programme Jason was told he was unemployable. His foster parents however were adamant to find him suitable work and through a family friend connected to the Church, he was offered a job working in a garden centre, picking out seedlings, however this led to a further episode of mental illness for Jason.

The lack of support offered to Jason on leaving school and being placed in a tenancy of his own at 18, created a number of problems for him, Jason



explains that at work he felt a complete failure as he could not do the simple tasks of 'pricking out,' a delicate task of ensuring the healthiest saplings survive. Jason said "I have a problem with manual dexterity, so if I went at the speed which was economical I would have killed all the plants, I'd go at a slower speed and the Boss would end up screaming at me because I was going too slow". At this time Jason was also living alone and he described that he began to feel suicidal. As a result he was admitted to a further stay in a psychiatric unit. Whilst there he was concerned about the guinea pigs he had at home so asked if his foster parents could go to feed them. On arriving at Jason's flat the foster parents found the property 6 inches deep in guinea pig excrement and all carpets soaked with guinea pig urine, so whilst Jason was in hospital the local council decided to evict him. However a Social Worker who had been contacted by the foster parents appealed the decision on grounds of Jason's mental health and he was allowed to retain his tenancy if he agreed to have regular cleanliness inspections. Currently Jason has the assistance of support worker to help him maintain his tenancy but they are not allowed to clean the flat for him so he has to do it himself. For Jason this is a matter of great contention, as he has to contribute to the cost of the support worker who effectively according to Jason just takes him to the recycling centre once a month.

In discussing personal relationships Jason acknowledged that these had not been particularly successful due to what is his lack of subtlety, which stems from his Aspergers, "of tell it like it is". However Jason had experienced one relationship that he felt was really a case of financial abuse, with him paying for trips to activities and venues for the other person. When he realised this was happening he stopped the relationship, it transpired the woman he had been seeing was actually a lesbian and had made it known to others she just wanted the financial benefits of the relationship. Jason stated although it was hurtful to realise this it was better than the exploitation continuing. This experience has deterred Jason from considering other relationships at present and he said whilst he would have liked to be married he does not want to have any children ever, because he would not want anyone to have to suffer what he has been through.

Jason then described that in the restructure and tendering of services undertaken by the local authority he was advised that he could no longer be part of the self advocacy group Be Heard, although he had been a member for several years and had also been their representative on the Learning Disability Partnership Board (LDPB). However with the advent of the autism strategy he was no longer considered to have a learning disability and he was told he needed to join the autism service. Jason stated he was told, "We will not allow you to be on the committee for people with learning disabilities as we don't think you have a learning difficulty". So although many members from the self-advocacy wanted Jason to be their voice on the LDPB

as he is articulate and speaks well on their behalf he has been removed. Jason is now the Chair of the local Autism Partnership Board, and he says they have threatened to kick him off this "for talking too much"!

## CHAPTER 9

### Daily Life, Bourdieu and Eugenics

*In this world there is room for everyone, the good earth is rich and can provide for everyone, the way of life can be free and beautiful... but we have lost the way!*

*(Chaplin 1940:np)*

What is the connection between the extracts of the life stories shared above, the eugenics movement and Bourdieu's theory of practice? Throughout the journey of this thesis I have wanted to give voice to the experience of people with learning disabilities and to hear what their daily lives are like. It is clear from their accounts of their day-to-day experiences that their likes, dislikes, aspiration and dreams are not unlike those of most people. However it is clear from their accounts that much of what the rest of society would accept as 'givens', part of the doxa of "our lives", are denied to many people with disabilities and particularly those with learning disabilities.

In relation to Timothy it is apparent that having (economic) capital he is able to resist some aspects of the symbolic violence Bourdieu describes. However this does not prevent other aspects of "oppression" as Timothy has 'embodied' within his 'habitus' other hallmarks of stigma, such as 'people like you holiday at Butlins' thus leading to low cultural and social capital, which I have suggested is linked to eugenic thinking. Timothy when he can, chooses to operate in a different social space or using Bourdieu's terminology, 'social field' by his regular and frequent trips to Spain where he feels the level of oppression is significantly less than in the UK.

Sharon has experienced symbolic power and violence in all aspects of her life with limited life opportunities until fairly recently. It is heartening to note that her Social Worker (SW) is supportive of her getting out more and this positive view of her SW is heartening as it is reported elsewhere that a number of service users have "deep seated distrust of social services" (SCIE 2005:10).

Unfortunately her opportunity to increase her economic capital has been curtailed in preference to her continuing with the voluntary work, which she makes to society. This choice has been guided by the employment support worker who may have felt voluntary work is more suited to people with learning disabilities for a number of reasons I have alluded to. In a Bourdieusian sense this is what is meant, by structuring structures, people in all situations have a sense of what is right/expected for them and of others. This is heard repeatedly in the comments in regards to having children, its just not for them.

Whilst Carol's current lifestyle has significant improvements on 24 hour care experiences, the levels of oppression although more subtle in life choices, remains high. Her experiences in the 'paid ' workforce and her relationship with her boyfriend reflect attitudes, which I believe are the doxic remnants of eugenic expectations. Her resilience against considerable abuse is remarkable and the support of the Self Advocacy provision that emanated from Valuing People has enhanced her life considerably. Although current austerity measures has already jeopardised and limited the scope of this service, moving forward it is highly likely services offered in the future may reduce even further.

Unlike other members of Be Heard, Thomas acquired his disability as a result of a road traffic accident. Quite why he was encouraged or opted for sterilisation remains a mystery, however the negative views held in society about disability however occurring are widespread. As Aiden & Mc Carthy have stated

*The pervasiveness of negative attitudes among the general public has not gone unnoticed by disabled people (2014:8)*

Has this had any bearing on Thomas' 'choices'? Thomas' family have remained supportive throughout and it has to be considered if this is more to do with the 'tragedy' of an RTA rather than the situation arising out of perceived heritability. Nonetheless his resulting treatment in social spaces,

Bourdieu's 'field' is consistent with the attitudes of the Early Spartans the forerunners of the eugenic zealots who suggested those subsequently disabled should do the right thing and take their own lives. The advocates of eugenic policy and practice considered them 'incurable useless eaters'.

It would appear that Adam is cognisant of the negativity surrounding his social status and I would suggest his views on abortion may be influenced by the dominant doxa regarding those with Downs syndrome and his own 'habitus' coupled with the reality of who is most likely to be aborted. Adam will not have escaped the underlying 'doxic' messages in the 'field' in regards to current abortion practices, reiterating who is and isn't valued in contemporary society. A doxa that is heavily influenced by eugenic ideology and a 'desire' for a perceived perception of what a quality human being is like. In Adam's experience of other oppressive practices and values, such as the right to share his room or not, are also imbibed into his acceptance of what is appropriate for him, this is what Bourdieu refers to as a sense of ones place.

Jason's experiences also represent years of ongoing structural and structured oppression, leading to mental health problems and the internalisation of fault at 'agency' level causing further periods of incarceration. As Jason said at the outset it was his fault because of his disability. Jason's reference to the serious levels of violence, which he endured and as reported by Mencap (2007), has meant he has internalised into his 'habitus' the belief that he is the problem. This Bourdieu would describe as a structured, structuring structure that facilitates and legitimises 'symbolic' and real violence and oppression.

Karl has had no support whatsoever from his family throughout his life, he has experienced significant levels of discrimination and oppression and some of the most basic givens are absent from his life (Blair 2003). The habitus, capital and fields, which have structured Karl's life have resulted in him having "jogging bottoms" on a 'wish list' and a 'birthday celebration' in Macdonalds even though he dislikes the place. In which context can these levels of oppression and discrimination ever be considered as acceptable or

justifiable? Where does the lack of Human Rights in these life events come from?

### Policy & Practice Concerns

In order to make these points clearer it is worth considering the life experience's of the interviewees against the measures purported to support equality, social justice and the rights of people with disabilities, notably the Human Rights Act (1998) the UN Convention on the Rights of People with Disabilities (UNCRPD 2007) and the Mental Capacity Act (2005). Also It is relevant to consider the strategy of Valuing People (2001) a policy that attempted to enhance the lived experiences of people with disabilities in a modern age.

In 1998 the Human Rights Act set out a number of articles to protect the rights of **all** human beings, Article 14 states,

#### *Prohibition of discrimination*

*The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status.*

(HRA 1998)

Of interest, is whilst it does state "or other status" it does not specifically mention disability. Specific non-discrimination for people with disabilities is left to General Principles (article 3) of the UN Convention on the Rights of People with Disabilities (2007) and the Equality Act 2010 (formerly provision came under the Disability Discrimination Act 1995 in the UK)

The Principles of the Convention on the Rights of People with Disabilities (UNCRPD) are,

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;



- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women;
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

Interestingly there is no equivalent right as in the Human Rights Act article 12 of the “Right to marry and found a family” (HRA 1998). Moreover from the information shared it does not appear that the Convention on the Rights of People with Disabilities is adhered to, especially in the case of Adam, Sharon and Karl. However to further explore the links between the life experiences as told to me, Bourdieu’s theory of practice, and the eugenics movement, it is useful to consider the principles of the Convention, the Equality Act and Articles of the Human Rights Act (HRA). Although it seems in regards to discrimination, we may be forgiven for thinking that The HRA 1998 does not in practice fully apply to disabled people. Article 2 of the HRA states as the first principle the Right to Life so this is worth considering.

In *Our Inheritance Our Future* (DOH 2003) the Government states it is committed to ensuring genetic diagnostic testing is available to all pregnant women to ensure that ‘defective babies’ are identified at an early stage in order for mothers to be offered counseling on the best course of action.

However this invariably means proceeding to termination as evidenced by the number of children born with Down’s syndrome in recent years. Perhaps this can explain why Adam, who has Down’s syndrome, is understandably against abortion. As Peter Elliot, Chairman of the Downs Syndrome Research Foundation notes “Why are the abortions at such a high rate unless they have been given the impression the situation was terrible and it warranted an abortion?” (Smith & Irvine 2009)

*Findings from The National Down Syndrome Cytogenetic Register, which has gathered data on the number of Down's diagnoses and births since 1989; shows that overall diagnosis of the condition has risen by 71% over the past 20 years, from 1,075 in 1989 to 1,843 in 2008. However, improvements in the screening process has led to a decrease in the number of Down's syndrome births due to a high rate of terminations.*

*(Morris & Alberman 2009:np)*

As Smith & Irvine (2009) report "three babies are being aborted every day due to Down's syndrome, according to a study which shows the number of terminations has more than trebled in the last 20 years". According to Elliot the choice presented to parents does not reflect "the true situation.... I don't think parents getting the abortions know much about Downs syndrome at all" (Cited Smith & Irvine 2009). As Bowman highlights too many people presuppose "people with Down's syndrome have no value" (Smith & Irvine 2009).

If the Right to Life is a starting point from the perspective of the Human Rights Act, for people with potential disabilities this is extremely concerning. Not least because of the issues reported in *Death by Indifference* (Mencap 2007) and the recent reporting of Southern Health Trust who failed to investigate 99% of unexpected deaths of people with learning disabilities in their care (Campbell 2015). The study Smith & Irvine report on also states that without the increased terminations aforementioned, live births of babies with Downs syndrome would be 48% higher than they currently are. As Quarmby aptly notes "discrimination starts before the birth for a disabled person and continues right up to the point of death" (2013:219). She further adds "many disabled people complain that they are put under pressure to end their lives" (2013:226) and therefore rightly notes the concerns about the legalization of "assisted dying", which as this paper is being written is about to commence its journey through the UK Parliament (September 2015).

In considering other aspects of The Human Rights Act 1998, it is of note that

whilst this legislation should be applicable to all human beings there are considerable aspects of it which fall well short of offering the protection that it should to people with learning disabilities. In the accounts of the daily-lived experiences of the people interviewed it is pertinent to note article 3 (HRA 1998) states, "No one shall be subjected to torture or to inhuman or degrading treatment or punishment". However fear of being followed, ignored, spat at and treated like a criminal, which are everyday occurrences for many disabled people must surely fall within the description of inhuman and degrading treatment. All the above were experienced by the individuals interviewed. The significant increase recorded in 'Hate Crime' gives testimony to this ongoing hostility towards the sick and disabled: 1,942 disability hate crimes were recorded by police forces in England, Wales and Northern Ireland one year after the coalition government came to power. Moreover "disability hate crime has doubled since the start of the financial crisis" (Clifford-Lund 2012).

Article 4 (HRA) further suggests that there should be 'Prohibition of slavery and forced Labour'. Whilst unacceptable, most people with learning disabilities find all the work that they are offered is "voluntary". They rarely receive remuneration for the tasks that they do. Even though some are clearly necessary tasks such as cleaning in cafes and dishwashing in the hospital (see Sharon & Carol interviews). Whilst this may not technically constitute 'forced labour' it is often the only opportunity for 'work' people with learning disabilities have.

Article 5 (HRA) suggests all people have the "Right to liberty and security". Article 5 covers detention for example in a hospital, educational setting or care home. All of the people interviewed were detained in some place or other throughout their life's and with the exception of Timothy most recalled negative experiences. Whether they were legally detained is a mute point as it is clear from their comments that they had little choice in the matter. Tregelles has noted, 17 years is the sentence for murder, yet even within the small group of individuals interviewed, lengthy periods of institutional 'care' were imposed, mostly against individuals' wishes.

The “Right to a fair trial” is article 6 of the HRA and whilst this may not be so apparent for the individuals interviewed for this research, it is clear from the respondents that they have accepted numerous situations which are not fair, for example would Adam lose his benefits if he was to share a bedroom with his girlfriend, did Sharon have to hand over everything to her mother after her daughter was born, what was the rationale for sterilizing Thomas? Does Karl need to ‘celebrate’ his birthday in Macdonalds or does Adam not have the right to buy multiple football magazines? Given the circumstances they find themselves in it would appear they feel there is little they can do to challenge things, and if they do would the repercussions not make matters worse? It is clear from Carol and others that they do not wish a return to the previous residential care and this may influence the choices they make. Whilst evidence, particularly in relation to the removal of children of parents with learning disabilities, is not a particular feature with the small group interviewed here, evidence suggests that a fair trial is not the norm.

*Findings show that people with a learning disability are unclear about how legal services could help them, and instead rely on people close to them for support. Family carers mostly rely on the internet, learning disability charities and support groups for help, rather than seeking advice from a lawyer.*

*Common legal issues identified by the research include parents with learning disabilities fighting to keep care of their children, discrimination in the workplace, disputed benefit claims, and hate crime.*

*(Mencap 2013)*

Article 7 (HRA) suggests, there should be “No punishment without law” however individuals are being punished, and denied their own liberties by having their personal bank cards removed, having restrictions placed on their choices of clothes or food, on fairly spurious grounds and in direct contravention of the provisions of the Mental Capacity Act. The MCA clearly states

*Everyone has the right to make his or her own decisions ..... Just because someone makes what those caring for them consider to be an "unwise" decision, they should not be treated as lacking the capacity to make that decision.*

Yet as can be seen from this small group, choices of small purchases, treats, birthday celebrations and holidays have all been limited or restricted in areas where capacity is clearly not an issue (see interviews of Adam, Karl, and Carol).

The “Right to respect for private and family life” Article 8 or rather the lack of it is apparent in many of the interviews. Jason was forced to attend football matches, supposedly in order to develop his communication skills. Adam is not allowed to share a bedroom with his girlfriend, Karl has been told he needs to wait for a 2 bedroomed house in case he falls out of bed, and Timothy should go to Butlin’s, as “it’s where people like him go”. All of these issues are the daily expectations of the individuals who shared their life experience with me. Unfortunately these breaches of rights do not end there, “Freedom of thought, conscience and religion” Article 8 also appears to have been breached to some extent in Jason’s experience as although Saturday was his Sabbath he was “made to go to football” under standards perceived by well-meaning social workers to be in the child’s best interests, regardless of religious beliefs.

“Freedom of expression” Article 10 and “Freedom of assembly and association” Article 11 were also impeded for Jason, Adam, and Thomas. Jason was forced to leave the self advocacy group he had been a member of for several years following the implementation of the Autism Act 2009 where he was required to join the Autism Partnership Board instead of the LDPB. Adam had his holiday planned for him by ‘care’ staff away from his girlfriend and at a different time, Karl was booked into Butlin’s for his birthday, when he would just like to have a place of his own. Even the right to buy chocolate, magazines or a new t shirt is condemned and frowned upon by ‘care’ and support workers in the so called best interests of the people interviewed.

Whilst the “Right to marry and found a family” Article 12 has been utilised by some people with learning disabilities, it is apparent from the interviews here,



this is not an expectation. The respondents were also of the view that having and keeping children was not for them. Quarmby has found “disabled people who have children are often attacked for their chutzpah, daring to pass on their “genetic ‘impairment to the next generation” (2013:224). Whilst individuals interviewed here did not have the experience of losing a child, it is significant that for the vast majority of disabled parents particularly those with learning disabilities, losing their children “to Social Services [is common] before being given an opportunity to prove themselves” (Quarmby 2013:225). This fact has not escaped those interviewed, as all interviewees are aware of other Be Heard members who have had their children removed at birth.

### Effective Legislation or Doxa?

Despite the UNCRDP (2007), the Equality Act (2010), the HRA (1998) and the MCA (2005), which are supposed to offer individuals protection, it is clear that for people with learning disabilities this is not always the case. When the Treasury recently sought the views of the public on how to reduce welfare expenditure, comments relating to disabled people were described “as [so] vicious” (Quarmby 2013:226), the site had to be taken down. As the Glasgow Media Trust also found, public opinion is such that the general population believe that as many as 70% of individuals on disability benefit are fraudulent claimants. In fact the figures are estimated to be more in the region of 1% to 2%, the end result however is that terms such as “scrounger”, “cheat” and “skiver” have tripled in the tabloid newspapers in stories regarding disability in the past five years (Quarmby 2012). Interestingly this ‘doxa’ replicates strands of the early eugenics movement, which sought to reduce the cost of individuals on the public purse. Of the views cited on the Treasury website one argued, “that all disabled people should be sterilised” and another proposed, “disabled people should be used as weapons of war” (Quarmby 2013:226). I suggest therefore it is not too difficult to make the links between these comments and the ideology of the eugenics movement. Following repeated requests from disability campaigners the site was eventually closed down; however its existence has offered a valuable insight into the values and attitudes permeating society at large. To date many are still of the view that disabled people are a “useless burden” (Quarmby 2013:226) and within this it



is clear to see how eugenic thinking lives on, as a result people with disabilities are clearly not seen as either human beings or equal citizens.

Further evidence of this value base is seen in relation to the ongoing sterilisation of people with learning disabilities. A case in question being, *NHS Trust v DE* [2013], DE had achieved a level of independence “not expected for someone of his level of disability”, (clearly a case of doxa overriding reality) in that DE had a longstanding and loving relationship with a woman who also had learning disability who gave birth to a child. As Quarmby earlier noted, (2013:225) the local authority, as is common practice instigated care proceedings. It was also stated originally that DE did not have the capacity to consent to sexual intercourse or to use contraceptives so was advised that to have sex with his girlfriend would be illegal. The legal action that ensued prevented DE from having any contact with his girlfriend, which caused him considerable distress although it was later assessed that DE did have the capacity to consent to sexual intercourse. However the ruling made by the Court of Protection stated it was in DE’s ‘best interests’ to have a vasectomy. Was this really the case or was something else contributing to the decision making process?

Hayman also highlights that a high percentage of children are removed from parents with learning disabilities (Hayman 1990 cited in Leavis et al 2011). There is no absence of documented accounts of abuse in a range of institutions caring for people with learning disabilities (Bingham 2015). As documented here from the respondents, negative attitudes continue to predominate. Although these long-held beliefs may have originated in antiquity they were certainly given a new and ‘pseudo scientific’ lease of life with Eugenic thinking and they still permeate today. As I have argued, current cultural and social beliefs are informed by an unspoken (doxic) eugenic ideology and in regards to disabled people and others, are transmitted and perpetuated through Bourdieu’s Theory of Practice.

## CHAPTER 10

### The Way Forward: Bourdieusian Social Work

*We all want to help one another human beings are like that... we want to live by each others happiness not by each others misery.*

*(Chaplin 1940:np)*

From a professional and personal perspective the impression of colleagues and students whom I have worked alongside, indicates most social workers are undoubtedly attempting to improve the life situations of the people they work with. Whilst oppression is something they seek to challenge, as suggested earlier, it is something, which they may unintentionally and unconsciously contribute to.

#### Bourdieu's Conceptual Arsenal

Garrett (2007) suggests being able to understand Bourdieu's 'conceptual arsenal' of habitus, field, capital and doxa, would be beneficial in challenging oppression, as these are the components in which it thrives. Bourdieu's ideas and core themes as Garret notes are "associated with the championing of liberation, human rights and social justice" (2007:238). Therefore an adoption of Bourdieu's 'conceptual arsenal' with an awareness of the manner in which ideology becomes doxa is the first step to challenging and critically evaluating the structural or symbolic violence inherent in a society, especially one which has been heavily influenced by eugenic ideology.

Bourdieu highlights "the education system is one of the principal agents of symbolic violence in modern democracies' (Moi, 1991:1023) and from my own experience I can concur with this (see introduction). By the time students arrive on Social Work courses they have already incorporated a range of ideologies through their habitus and education field which unwittingly

could/would perpetuate symbolic violence. The expectations of the value and contribution individuals with learning disabilities make to society, is already tainted by the doxic miasma inherent in a society unable or unprepared to address its eugenic past. The education process which categorizes individuals with learning disabilities in a particular way "is apt to stigmatise or devalue, but is [also] apt to be viewed as legitimate, by those subjected to it, because of previous patterns of socialisation" (Bourdieu 1998:17). Therefore it is imperative that social work students gain insight to this process, in order to fully understand the relation of social work history to eugenics and oppression. As discussed in the Bourdieu chapter, habitus is "laid down in each agent in their earliest upbringing and continues to reverberate throughout a persons lifetime" (Bourdieu 2003:81), considering this phenomenon as part of the process of self evaluation which is incorporated into every social work degree would/could facilitate an understanding of self awareness and knowledge which could/would aid critical and reflective practice and knowledge.

In working with service users Bourdieu has noted too that class division and oppression is also 'scripted' into the body in the manner which it presents itself, not least via "gait, the gestures of the arms and hands, inclination of the head and so on" (Garrett 2007:228). This should be of interest when social work students are taught about body language and the messages this communicates. Bourdieu considered that the accepted "bodily hexis' is characterized by the manner of speaking, standing, feeling and thinking, all influence the way in which one's habitus is "society written into the body" (Bourdieu 1994:63). Therefore it is easily seen how one's origins and disposition can unwittingly lead to levels of power and oppression or subordination just by being one self.

As Bourdieu explains;

*The habitus is not something natural, inborn: being a product of history, that is, of social experience and education, it may be changed by history that is by new experiences, education or training . . .*

*(Bourdieu 2002:29)*

This is particularly important for social work students who as a result of their experience will be able to recognise that whilst “Dispositions are long-lasting [and] they tend to perpetuate, [and] reproduce themselves, they are not eternal. Any dimension of habitus is very difficult to change but it may be changed through the process of awareness and of pedagogic effort (Garrett 2007:229). This is of significance to social work practitioners as often it is implied within practice areas that problematic situations are cyclical and that ‘problem families’ will generate ‘future problem families’. In particular notions of learning disabled people being ‘unfit /unsuitable parents’ is a prevailing doxic assumption that needs to be challenged. Similar no doubt to the currently promoted ‘cycle of welfare dependency’ used to scaremonger the public into believing the welfare state has created a class of non-working households who find it acceptable, and a lifestyle choice to be benefit-dependent (Humphrys 2011). However as the recent findings of the Joseph Rowntree Foundation have shown there is little evidence to substantiate these claims (Rosso et.al 2015).

However such claims as promoted by the dominant discourse encapsulate and epitomize the concept of doxa; in particular how it is experienced by subordinate groups and which in great part contribute to continuing and ongoing levels of oppression. As Garrett suggests, doxa is perceived as the “world of tradition [it] is experienced as a natural world and taken for granted” (2007:227). That is to say, ‘the established cosmological and political order is perceived not as arbitrary, i.e. as one possible among others, but as a self-evident and natural order which goes without saying and therefore goes unquestioned’ (Bourdieu, 2003:166).

In a similar vein to ‘accepting without question’ a perceived culture of ‘welfare dependents’ “doxa operates as if it were the objective truth across social space in its entirety, from the practices and perceptions of individuals to the practices and perceptions of the state and social groups” (Chopra 2001:426).

The acceptance of these attitudes is particularly prevalent in relation to adults with learning disability.

Bourdieu however does argue that it is possible to question doxa, which is appropriate given the definition of social work is to challenge, seek social justice and fight oppression. The mode, which Bourdieu suggests this is possible, is by creating what he refers to as 'critical intellectuals'; "these intellectuals are detached and scientifically informed scholars who are unconcerned with winning traditional honours (such as professional status) and who are prepared to interrogate and challenge established 'truths' and 'conventions' (Fowler, 1997:32). Bourdieu states "this [is] in fact, the 'civic mission of intellectuals'" (cited in Wacquant, 1998:227), and of all those 'who are willing to and capable of investing their intellectual weapons in political struggles' (op-cit). This of course can also be done most effectively by enabling and incorporating the views of those who are the oppressed and by giving them equal voice.

This is a description, which seems to accurately describe social workers and aspiring social workers who are encouraged and willing to critique ideas, and recognise the complexities of social problems. The critical intellectual (social worker) "incorporates into a political struggle their specific competence and authority, and the values that are involved in exercising their profession; thus, 'scholarship' and 'commitment' go hand in hand (Schinkel, 2003:80). As in social work education the role of educators is to achieve what Bourdieu and Wacquant (2004) sought from sociology, notably

*It must first give new eyes', . . . The task is to produce, if not a 'new person', then at least a 'new gaze', a sociological eye. And this cannot be done without a genuine conversion, a metanoia, a mental revolution, and a transformation of one's whole vision of the social world.*

*(Bourdieu & Wacquant 2004: 251)*

The importance of such a stance is imperative if we are seeking to improve the lives of adults with learning disabilities. For Bourdieu, a long - term critic of

neo liberalism, it is for critical forces in society, such as social workers, “to insist on the inclusion of social costs of economic decisions” (Garrett 2007:228). For example, policy decisions should take account of the human misery inflicted by austerity measures on service users, such as the removal of the Independent Living fund or the distress caused to many by a reduction in support services. This includes suicide, depression, domestic violence and child poverty, all matters which social workers face on a daily basis. As Bourdieu has stated, these things not only cost a great deal in money, but also in misery (Bourdieu, 2001:39). Moreover as the recent response to Freedom of Information (Dept. of Health 2015) requests have shown, following work capability assessments that appear to be based on the implementation of policy informed by this doxa, as many as 90 people per month have died following their supposed ‘fitness to work’. As Bourdieu highlighted, what is needed is a move away from “narrow short term economics....to an economics of happiness” (2001:40), as under neo-liberal and austerity measures we are “witnessing the destruction of the economic and social bases of the most precious gains of humanity” (Bourdieu, 2001:37).

Although Bourdieu viewed social workers as agents of the state, which is a fair assessment in many cases, the issues that they grapple with on a daily basis are also the issues and ideas associated with Bourdieu, notably “the championing of liberation, human rights and social justice” (Garrett 2007:229). Whilst recognising the contradictions of the social work role Bourdieu also appreciated the fact that “many social workers, and those undertaking similar work, ‘feel abandoned, if not disowned outright, in their efforts to deal with the material and moral suffering that is the only certain consequence’ of rampant neo-liberalism” (Bourdieu in Bourdieu et al 2002:183 see also Jones, 2001).

As previously stated Bourdieu recognised one of the chief problems faced by social workers is that they,

*Must unceasingly fight on two fronts: against those they want to help and who are often too demoralized to take a hand in their own interests, let alone the interests of the collectivity; on the other hand, against administrations and bureaucrats divided*



*and enclosed in separate universes.*

*(Bourdieu et al 2002:190)*

Garrett argues there is a need, “if not for a Bourdieusian social work, then for a social work informed by Bourdieu’s theoretical insights and by his opposition to neoliberalism” (2007: 227). As Garrett notes “the definition of social work appears to orientate the profession in the direction of Bourdieu” (op cit). As can be seen from the IFSW (2014) definition of social work, the concerns of social work – notably, human rights, social justice, social cohesion and the promotion of social change are also issues concerning Bourdieu. By adopting a Bourdieusian approach to social work, the issues of oppression and domination that have been highlighted in the comments shared in this work could be viewed through a ‘new gaze’. Moreover such a gaze allows for the possibility of understanding the ‘doxa’ that has shaped the lives of the participants, this could lead to a better informed, pro active approach to achieving the life styles and aspirations discussed.

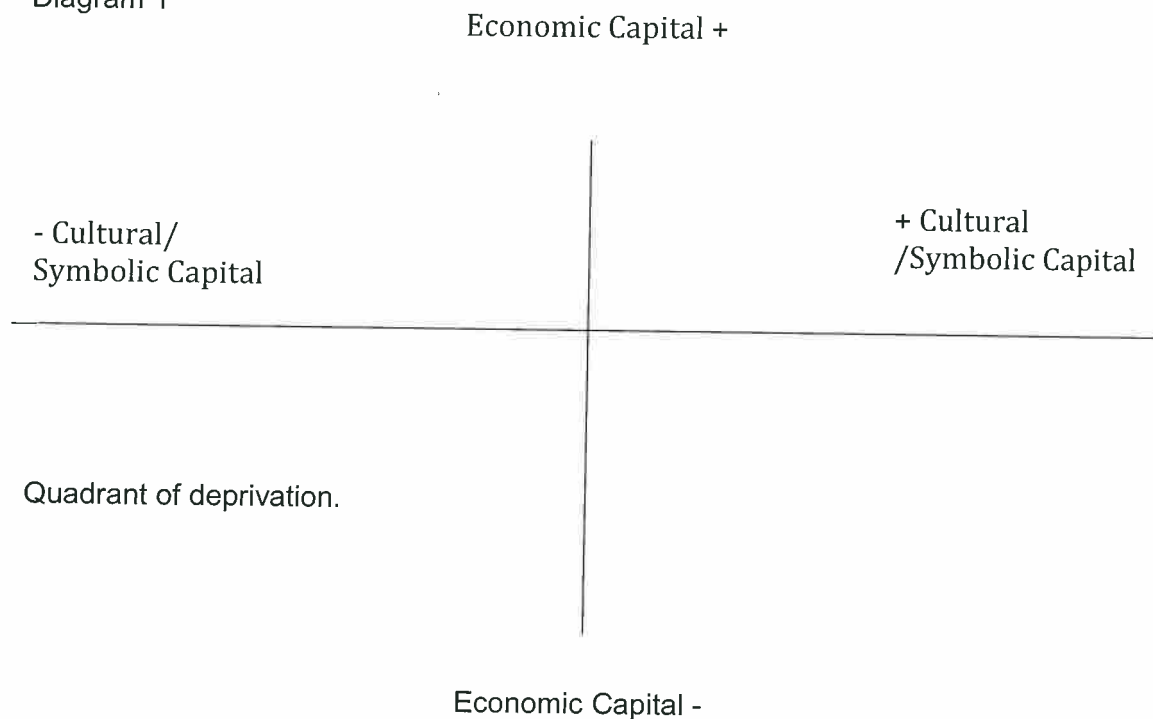
#### A Model for Bourdieusian Social Work

In order to promote a Bourdieusian social work approach I suggest the use of a ‘Hysteresis Wheel’ model. Hysteresis is also a term utilised by Bourdieu to explain the experience of being “out of touch in time and place” (Hardy 2008:132) particularly with recent life events, in reference to one’s own habitus. Whilst Marxist traditionalists utilise the term ‘alienation’ (see Hardy 2008) and Durkheim (1952) the term ‘anomie’ to describe the experience, Bourdieu regarded that both of these terms had moral undertones, which he wished to avoid. He therefore chose to utilise what he considered the more neutral scientific term ‘hysteresis’ to describe the time lag of disturbed equilibrium that is associated with life changes. As Hardy describes, “the phenomenon of hysteresis is defined as occurring when changes in a property (ones life experiences) lag behind changes in an agent on which they depend” (2008:133). This is a phenomenon which social workers can create in the people they support by highlighting and opposing the life styles and values of the dominant discourse, e.g. the view that there is a culture of welfare

dependency, substance misusers are bad parents, or people with learning disabilities are incapable or useless. Likewise they can create hysteresis for others by challenging the doxa of these assumptions as part of anti oppressive practice. As Peillon has noted social workers operate “in a field with political capital, and the exercise of their power” (1998:223) may unwittingly produce symbolic violence and oppression. In the Bourdieu chapter I have noted that most individuals who social workers engage with are in the section of low cultural and economic capital, if placed in a social field (space) it would form a quadrant of deprivation.

### Diagram of Capital in a Social Field

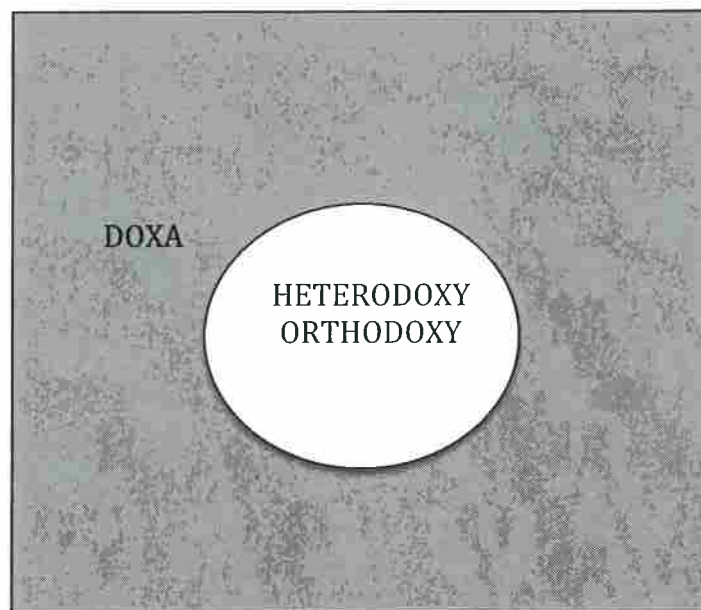
Diagram 1



*(See Thomson original diagram cited in Greenfell 2008:72)*

When Diagram 1 of the Field arena is transposed into diagram 2 it will have a number of doxic assumptions, (see diagram 2)

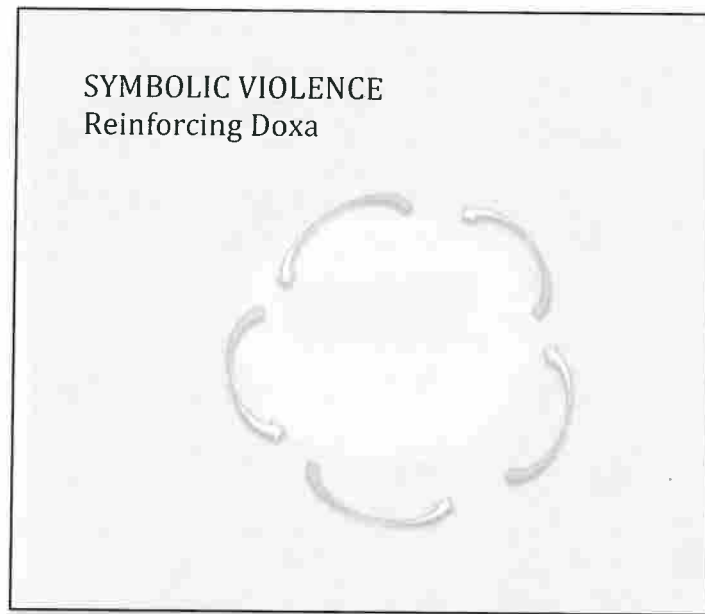
Diagram 2. Doxa within a Social Field



Within the social field (space) there are numerous attitudes and values which are taken as givens and these are represented in the shaded space of Doxa, notably opinions, beliefs, practices and attitudes towards in this case adults with learning disabilities which are taken as “givens” so are not in need of discussion. It is apparent therefore that unless social workers seek to challenge the doxa of the dominant discourse they will continue to engage even if unwittingly, in the oppression and symbolic violence discussed earlier.

Symbolic violence is represented in diagram 3 as being the process by which doxa is maintained is allowed to perpetuate and is reinforced.

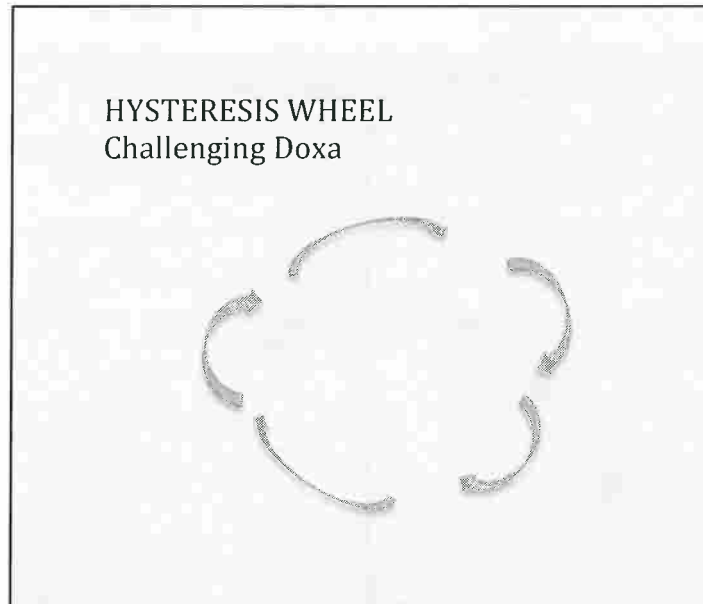
Diagram 3. Symbolic Violence



As can be seen symbolic violence serves the purposes of legitimising and reinforcing the parameters of doxa. However in the process of challenging doxa whether at an individual or structural level there will undoubtedly be a measure of hysteresis, i.e. a change between the given doxic assumptions and an alternative world view. Notably by challenging doxic assumptions it brings to the fore that these opinions, attitudes, practices and beliefs may not be entrenched or natural "givens" after all. Therefore in challenging doxic assumptions practitioners will seek to avoid imposing symbolic violence on their service users.

I suggest that the role of the critical intellectual (social worker) is to challenge the doxa of attitudes which exist towards social work recipients, thereby unsettling long held attitudes and dispositions not only of the people whom they support but also by those who seek to keep them in positions of subordination.

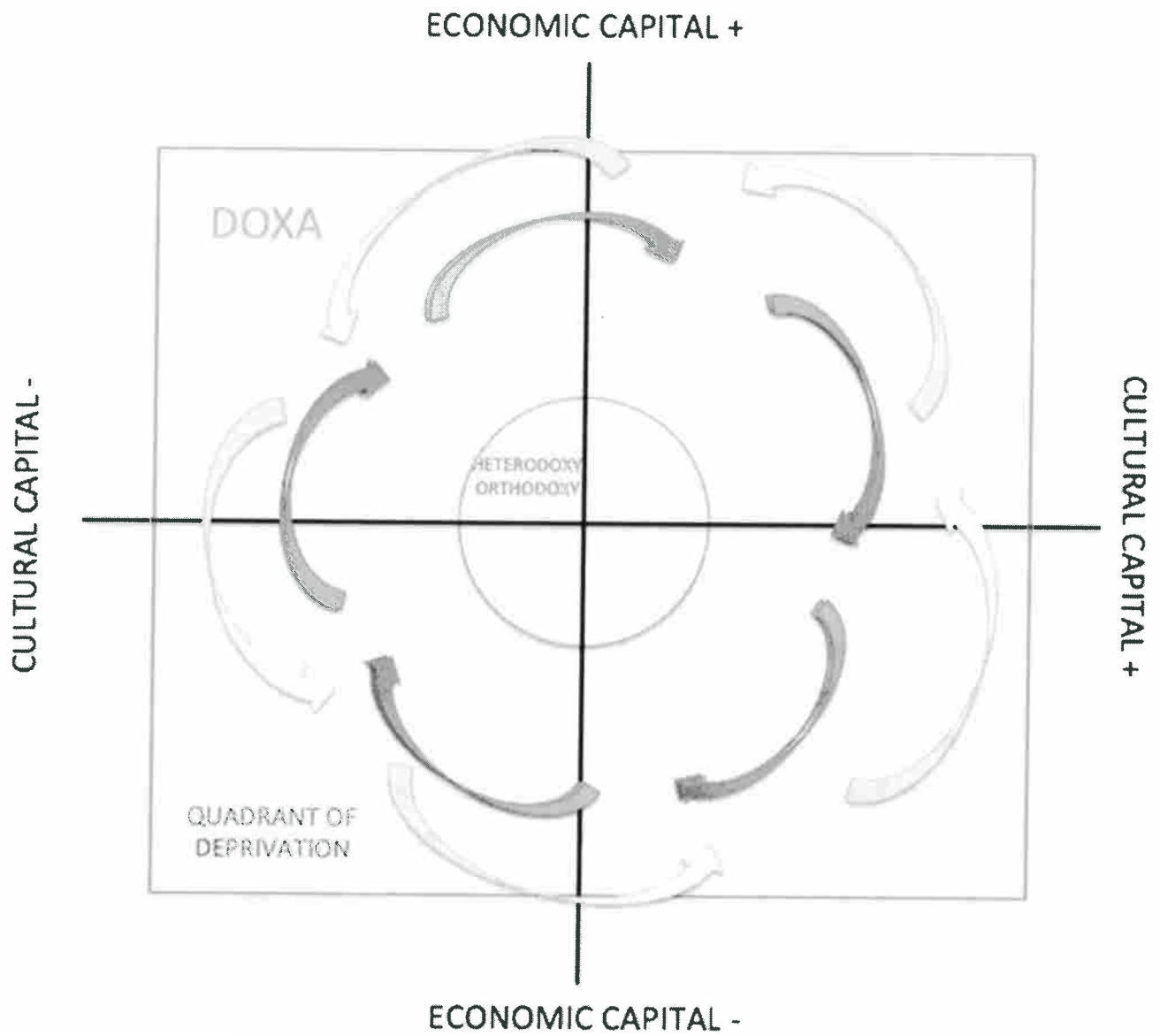
Diagram 4 Hysteresis Wheel



In promoting a discourse which challenges the entrenched doxic attitudes, the permanency of the prevailing doxa is no longer a given view of the world. However it is important to recognise that many attitudes and beliefs are so imbibed into societal structures that it is not always easy to recognise where they originate from. Within this work I have attempted to identify a number of doxic attitudes towards learning disabled adults that can be considered and challenged, as the historical backdrop of eugenics and the origins of oppression have been laid bare.

This model can be seen holistically in diagram 5.

Diagram 5 Hysteresis Wheel Model





### Hysteresis in Practice

Through the case studies that Bourdieu explores in *The Weight of the World* (1999) he highlights the struggle of hysteresis which individuals (whose habitus and field are changing) experience at a personal and unique level. The experience of 'hysteresis' will not be unfamiliar to social work students as it is often witnessed as part of their journey to becoming social workers. It will also be familiar to any others who have had to re-assimilate themselves into new life circumstances, for example people leaving long stay 'care' and re joining the wider community. As Hardy explains it "highlights the gap between the new opportunities that occur as a result of any field change, and field participants with attitudes and practices that are needed to recognise, grasp and occupy these new field positions" (2008:135). It is not dissimilar to the theoretical view of crisis intervention whereby a change in circumstances creates an opportunity to re order or restructure ones view of the world and ones position in it. It can of course reinstate the symbolic violence of the previous situation if the doxa is allowed to reassert itself.

As Hardy has suggested "hysteresis, a disruption between habitus and field, does provide opportunities for improving field positions" but to ensure this is achieved and maintained it is important to also continue to retain a critical intellectual approach and challenge the doxa emanating from the dominant discourse. In order to do this we need to observe Bourdieu's commitment to 'active and methodical listening' as opposed to 'half-understanding' based on a 'distracted and routinized attention' (in Bourdieu et al 2002: 609/614; see also Pileggi & Patton 2003), which is found in a tick box approach to social work promoted by the neo liberalist agenda. The importance of hearing and listening to previously unheard voices is critical to this. The use of Bourdieu's conceptual arsenal to address the issues highlighted in regards to the pervasive and miasmatic nature of doxa in social work practice would undoubtedly facilitate many a 'new gaze' on the pernicious nature of oppression and hopefully move towards what is needed, a move away from "narrow short term economics....to an economics of happiness" (Bourdieu

2001:40).

## Chapter 11

### Conclusion

*Our knowledge has made us cynical, our cleverness hard and unkind, we think too much and feel too little.....more than cleverness we need kindness and gentleness, without these qualities life will be violent and all will be lost.*

*(Chaplin 1940)*

Unfortunately people often think that the mass killings and murderous regime of Hitler was an incomprehensible blip in the name of progress; and that the eradication of the unfit or undesirables was a phenomenon unique to the Nazis. However as the Mencap report, *Death by Indifference* (2007) highlights, institutional discrimination in the National Health Service is rampant against people with learning disabilities. Hate crime has increased by 213% and alongside this, figures show that 3 abortions every day are carried out on fetuses suspected of Downs syndrome. Moreover in the recent measures to reduce welfare spending 90 disabled or terminally ill people per month have been allowed to die without any public outcry, all this seems far removed from eugenics having been laid to rest after the second world war.

This thesis has set out to highlight the pervasive factors of eugenic ideology that I contend continues to perniciously invade contemporary attitudes, approaches, practice and services to people with learning disabilities. It has viewed the experiences of the participants who shared aspects of their life story through a feminist narrative lens, and fully acknowledges the manner in which the researchers own 'habitus' and 'doxa' has contributed to the research topic. The thesis has explored the policy and rhetoric of improving the lives of those considered as learning disabled within the context of valuing people and personalisation. In so doing it has utilised specifically the work of Bourdieu and his conceptual arsenal of habitus, capital and field, however it has also included the concepts of doxa and hysteresis to address the way in which symbolic violence and oppression can be challenged. Social Work has been considered from both existential and structural perspectives and has

utilised, Young (1990), Mullaly (2007) and others to place the impact of eugenic ideology within the remit of contemporary social work practice. It has added a new dimension to the understanding of factors that contribute to the oppression of the dispossessed and marginalised within contemporary society.

The thesis goes beyond existential, structural or radical social work by engaging with a Bourdieusian approach to Social Work as suggested by Garrett (2007). Exploring and understanding the impact of eugenic ideology, which as can be seen is intrinsically linked to the foundations of the Welfare State and therefore social work practice. Whilst the concept of care depicts, “warmth, closeness and love, it has also been associated with control, power and oppression” (Swain et al 2008:141). As Berghs notes, “disabled people have generally been critical of notions of ‘care’ pointing to a legacy of institutionalisation and dehumanising care, medical paternalism and the failures of adequate provision of alternatives, such as community care or independent living” (Swain et al 2014:270).

By utilising a Bourdieusian approach it may be possible to fully consider and work towards the eradication of oppressive policies that have to some extent emanated from the eugenic past. Through an understanding of doxa the toxic ideology of eugenics can be seen for what it is and brought into the consciousness of social work practitioners, moreover they will then be informed and aware of their individual contribution to symbolic violence and seek strategies to avoid this.

The Hysteresis Wheel model enables an approach, which can through the understanding of the ‘new gaze’ identify and challenge the ‘doxa’ of any oppressive situation. A holistic approach to social work practice as envisaged via the Bourdieusian model suggested takes forward the formal polarisation of the existential versus the structural debate and allows for the new gaze to seek a more just and equitable society, one which takes account of the wishes, aspirations and desires of individuals with learning disabilities.

Whilst this thesis has facilitated the development of a new model it also has experienced some limitations, not least the inability to fully engage with Social Work practitioners in the interview setting. Given the ongoing political changes that social work and local government services experience as part of the never - ending reforms and austerity, it is undoubtedly challenging to address some aspects of social work research in such an environment. Nonetheless it is important to continue to try and gain an understanding of the issues on the ground during such turmoil. As an alternative methodology of engaging with social workers, for example email questionnaires or telephone interviews may have served to gain the information needed. Although response rates are usually low, however an attitude of flexibility and resilience in the face of adversity is needed.

Ironically it transpired the most difficult to reach group were social work practitioners, however given the state of flux of social work at this time I should not have been entirely surprised. Moreover the ongoing challenges experienced by service users in times of austerity also played a part in making the gathering of data complex. A way forward for this would be for researcher/academics to be seconded into social work practice areas to gain more insight and access to the relevant people. However this too would have some ethical issues, which would need careful consideration. Particularly from a feminist perspective as the issue of power imbalance could become a significant factor. During the gathering of data for this thesis there was certainly a positive rapport developed between the participants and the researcher, although it is recognised that the relationship with the larger group had already been well established prior to the data gathering.

In regards to meeting the ethical considerations of the research, all of the participants have expressed their satisfaction and willingness to contribute to this thesis and have expressed a desire to be involved in any future research projects that may emerge. The emotional impact of the research on all concerned including myself is an area, which I would be more attuned to in future. Whilst no injury or undue distress was caused it was imperative and beneficial that all the interviews took place in a suitable and supportive

environment. This would undoubtedly influence any future decisions in regards to data collection. The resilience of the group members who participated in the research was remarkable and clearly demonstrated to me the beneficial effect of self-advocacy services.

By enabling service user voices to 'Be Heard', I have been able to draw on a range of experiences and challenges that demonstrate a link to the issues and impact of eugenics in contemporary society. Importantly the learning gained from this research experience has enabled a Bourdieusian informed model based on Bourdieu's theory of practice to be further developed. This is a model that cannot only identify oppression and symbolic violence but one which can also suggest a strategy to examine doxic assumptions and where they emanate from.

The claim of originality in this work is that it links Bourdieu's theory of practice to the field of learning disability it raises significant awareness of the role of eugenics in the welfare state and importantly in social work practice. It has enabled a model for challenging oppression to be developed. The result of this work is to highlight and recommend the need for more detailed teaching of the history of social work in education. In particular the teaching of the history and influence of eugenics in the welfare state as these doxic assumptions are still contributing to the oppression of learning disabled service users. By introducing this information to the social work curriculum students and future social workers will be equipped to take a critical intellectual stance, offer a new critical gaze, and challenge the oppressive aspects of current doxa, which has some of its perceived legitimization in the historical backdrop of eugenic ideology.

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## Appendix

### Appendix 1.

Research Ethics Committee Certificate of Approval

University of Sussex 10/10/12

### Appendix 2.

Hysteresis Wheel Power Point





University of Sussex

**Social Sciences & Arts Cross-School Research Ethics Committee**

**CERTIFICATE OF APPROVAL**

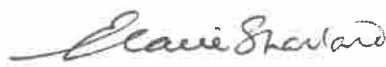
<b>Reference Number:</b>	1112/03/05
<b>School:</b>	ESW
<b>Title of Project</b>	Doxa Disability & Discrimination
<b>Principal Investigator: (Supervisors)</b>	Elizabeth McCreadie (Dr R Whiting, Prof I Taylor)
<b>Expected Start Date:*</b>	01/11/12

\*NB. If the actual project start date is delayed beyond 12 months of the expected start date, this Certificate of Approval will lapse and the project will need to be reviewed again to take account of changed circumstances such as legislation, sponsor requirements and University procedures

**This project has been given ethical approval by the Social Sciences/Arts Research Ethics Committee (C-REC). Please note the following requirements for approved submissions:**

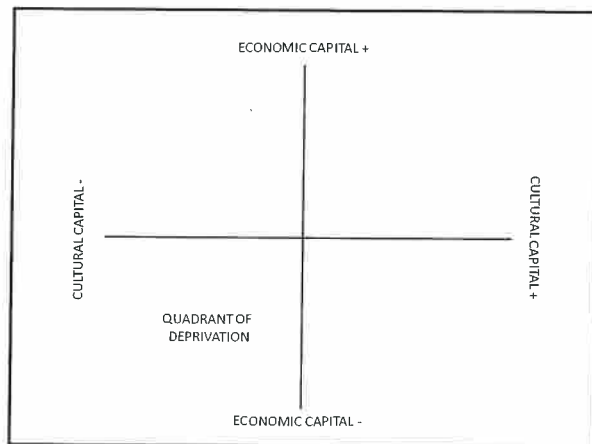
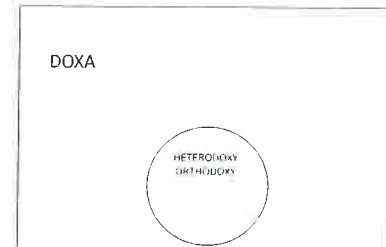
**Amendments to research proposal** - Any changes or amendments to the approved proposal, which have ethical implications, must be submitted to the committee for authorisation prior to implementation.

**Feedback regarding any adverse and unexpected events** - Any adverse (undesirable and unintended) and unexpected events that occur during the implementation of the project must be reported to the Chair of the Social Sciences C-REC. In the event of a serious adverse event, research must be stopped immediately and the Chair alerted within 24 hours of the occurrence.

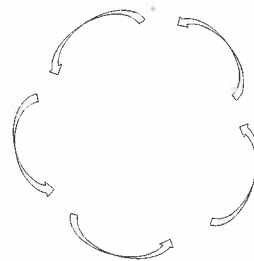
<b>Authorised Signature</b>	
<b>Name of Authorised Signatory (C-REC Chair or nominated deputy)</b>	Dr Elaine Sharland 10/10/12



Elizabeth McCreadie  
'Hysteresis Wheel'



**SYMBOLIC VIOLENCE**



**HYSTERESIS WHEEL**

