Policy to Practice: A critical analysis of the 'Valuing People' strategy.

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ABSTRACT

This qualitative investigation set out to analyse the impact of 'Valuing People: A New Strategy for Learning Disability for the 21st Century' (DH, 2001) on the lives of people with profound intellectual and multiple impairments (PIMD) and their family carers. Data was drawn from three distinct sources. The investigation began with a critical discourse analysis of Valuing People (VP). The findings informed the development of a semi-structured interview schedule for use with family carers caring for an adult with PIMD. It was deemed important to the study to include an individual with PIMD in as meaningful manner as possible. Therefore, following careful ethical deliberations, filmed excerpts of a woman with PIMD engaged in aspects of her daily routine, representing the main themes of VP, were used to elicit focus group discussions with paid care workers in different parts of London.

The findings from the different data sources were triangulated, highlighting how a focus on a social model of disability in VP excluded those with PIMD. This neglect was confirmed and elaborated by the family carers and also the paid care workers. The findings further highlighted deficiencies in the volume and nature of provision of appropriately skilled staff, the availability of specialist services and residential respite for families. There was also a general feeling that things had not improved and much concern about the future. The film elicitations demonstrated the use of VP language among care workers but with little understanding of the concepts of rights, independence, choice and inclusion.

By situating this hermeneutic exploration within a critical approach, the main findings have demonstrated the manner in which people with PIMD are marginalised within the policy, rather than having their differences recognized and ultimately their needs met.

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The PhD is dedicated to my mother, Lillian Darrell

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Chapter 1 Intellectual Disability

'the magnitude of defensive manoeuvres used by people to evade this reality, i.e. the sheer painfulness of having a learning disability, to all concerned' (Simpson and Miller, 2004:pxxiv).

For the purpose of clarity and in solidarity with international researchers, this thesis will employ the term used by the World Health Organisation (WHO) within the International Classification of Functioning, Disability and Health (ICF) i.e. 'intellectual disability' (Schalock, et al 2007). However, the terms 'learning disability' and 'learning difficulties' are still prevalent in the UK.

1.0 Introduction

The impetus for this thesis was the publication of the Valuing People (DH, 2001) policy document. This was promoted as the first paper on learning disability for thirty years (DH, 2001 p14 1.2). It set out a programme of action for improving services, by linking the four key principles of rights, independence, choice and inclusion to a new life-long approach for services and opportunities aimed at people with intellectual disability (ID) and their families. It was anticipated this new approach would lead to positive outcomes in education, housing, health, employment, social services and overall support. As the parent of an adult woman with profound intellectual and multiple disabilities (PIMD), this researcher was initially optimistic that the ID population's needs were visible on the political agenda. However, the initial optimism was clouded by the sense that the strategy had no real substance for people like her daughter.

The publication a few years later of the cross-departmental government report, 'Improving Life Chances of Disabled People' (DWP et al, 2005) was a source of even more dismay. The only mention of PIMD occurred in reference to the lack of information about numbers of people with high support needs (DWP, et al 2005, Annexe F p 42). Whilst there was some representation of people with PIMD in Valuing People Now (DH, 2009) they were still not

acknowledged as a group with distinct needs. The question arose as to why this group of people was so overlooked.

It appeared the prevailing discourses surrounding issues of ID did not acknowledge the wide-ranging spectrum of impairment people with ID experience. In the slew of research published by the Learning Disabilities Observatory this range was acknowledged in the population of children with ID but not with adults (Emerson, et al, 2011 p i, 3). It therefore seemed necessary to unpick the latest mode of representing people with ID. This involved exploring the background to yet another name change and to the philosophical framework for the VP policy itself. It is the researcher's contention that until society is comfortable with discussing profundity of intellectual impairment, the defensive manoeuvres Simpson and Miller (2004) refer to will continue. This is even more relevant in light of the Winterbourne View abuse scandal (DH, 2012).

The nexus of social policy and the impact of subsequent initiatives on the lives of people with PIMD and those who support them is a relatively unexplored area and is the main topic of this thesis. Interpreting the unique and idiosyncratic nature of this experience lends itself to a qualitative study. The subject under discussion here is very difficult to define and explain. For this reason the research design needed an approach, which could incorporate discursive descriptions and explorations of construed meanings (Blaikie, 2000). An inductive mode of enquiry was further selected to encompass this complexity. The methodology needed to incorporate a critical exposition of policy, with as close to first hand accounts of the lived experience of the target population, as it was possible to obtain. Additionally, the study was seeking to establish an appropriate methodology for meaningfully including individuals with PIMD in consultations and research.

The use of film of individuals with PIMD is increasing, as it conveys their lived experience more succinctly than the written word. For example the Department of Health have created a number of films for their website (DH, 2007). However rather than simply including a video case study, as the Department of Health have done, this thesis incorporated film elicitation via filmed excerpts of an individual with PIMD. This was in order to establish and guide the focus group discussions with formal care workers about their understanding of the Valuing People policy. The filmed excerpts were used to illustrate the key themes of the Valuing People (DH, 2001) policy and the focus groups were set up in order to explore care workers' comprehension of these ideas.

The research design included a preliminary critical discourse analysis (CDA) of VP's proposals, themes and projected outcomes, which informed the interview schedule of questions. The documentary evidence, which was subjected to the CDA, provided a factual overview of the key issues regarding adults with PIMD. CDA was selected, as this method enables exploration of texts, which might further demonstrate the relationship between discourse and society, text and context and language and power (Fairclough, 2001b).

The research questions were concerned with the sense family carers and paid care workers make of formal policy. Therefore the study needed a strategy, which explored these individuals' accounts and interpretations of said policy. These accounts could then be set against a critical examination of the key policy papers including Valuing People (DH, 2001), Improving the Life Chances of Disabled People (DWP et al, 2005) and Valuing People Now (DOH, 2009). Focusing on the language and images used in these documents revealed their inherent discourses and the manner in which these are used to further political aims (Fairclough, 2003). Fairclough maintains discourses represent the manner in which '*things are'* (p207), but they are also used to represent the ways ' *things might or could or should be'* (p207). It could be argued this is the reason the distinct and specialist needs of adults with PIMD have been overlooked. Therefore by situating this hermeneutic exploration within a critical approach, the thesis seeks to demonstrate the manner in which people with PIMD have been marginalized within policy, rather than having their differences recognized. Arguably, those differences may well *'jeopardize the validity of the model'* (Fischer, 2003 p100).

A reflective stance was a constant feature of this research. On a personal level the researcher was very clear about her position, which could also be described as triangulated. As a parent, professional and academic, she has long-term experience of the target population and those who support them. The subjective nature of her self-disclosure encouraged participation, rapport building and trust (Johnson, 2002). Epistemologically, this reflexivity was crucial in devising the research questions, which specifically aimed to accommodate the declared difficulties within a space of critical scrutiny. Therefore the research questions are as follows,

Q1: To what extent is the VP policy, informed by a social model approach to disability?

Q 2: How do family carers of individuals with PIMD make sense of the philosophical underpinnings of the current policy?

Q 3: How knowledgeable are formal care workers, supporting people with PIMD, of the VP approach? Is there any evidence of a theory-practice gap?

Structurally, the first chapter of the thesis commences with a detailed background of the term learning disability and the various definitions in use in the UK and internationally. It then examines the manner in which PIMD is represented in these definitions. This leads to a more general discussion of the social model of disability, including its initial formation, which emerged in parallel with the then framework for ID services in particular known as normalisation. This is followed by an examination of the second wave of the social model with its refocus on embodiment issues, the later post-structural perspective and the place of ID within this approach. The discussion hones in on the difficulties with accommodating issues associated with PIMD, such as lack of mental capacity and inability to self-advocate, within this model.

Chapter two presents a detailed literature review, which focuses initially on the difficulties inherent in including people with PIMD in participatory research. The focus then shifts to a further critique of the social model approach to PIMD. This includes reference to other social contextual approaches, which have signalled similar values and which appear to have influenced policy makers. The final section explores and assesses the literature with regard to the key cornerstones of the VP policy.

Chapter three outlines the research objective, design and methodological approach. It describes the triangulated method chosen covering the critical discourse analysis, interviews and focus groups and the sampling / recruitment /data collection from these three sources. It also discusses the ethical approach especially with regard to the use of the filmed excerpts of an individual with PIMD.

Chapters four, five and six describe the findings from the aforementioned sources and chapter seven triangulates these findings. Since they suggest issues associated with PIMD have been marginalised within current policy, chapter eight queries how these ongoing issues can be resolved in the changing political climate. This final chapter concludes with a list of recommendations and future research suggestions.

1:1 Learning Disability Background

The introduction of the term learning disability as a replacement for the previous term mental handicap can be traced to the Conservative Secretary of State for Health from 1995-1997, Stephen Dorrell. This occurred despite the fact that People First, a user led self-advocacy organisation, had expressed a desire to use the more social model influenced term, learning difficulties (Sutcliffe and Simons, 1993). They felt the use of the term learning disability was oppressive and that the term learning difficulties better described their own impairment effects. As they saw it, learning disability was a negative term and learning difficulties showed they wanted to learn and could. However, the Department of Health was concerned this would lead to confusion with specific educational learning difficulties such as dyslexia.

This concern was well founded. As recently as 2008 (seven years after Valuing People (DH, 2001) was published), Mencap the national campaigning organisation for people with ID, conducted a survey in which more than 1600 members of the general population and 103 MPs were asked for an example of learning disability. 73% of the public and more worryingly 74% of the MPs gave completely wrong answers. The most common answer was the specific educational learning difficulty, dyslexia (Mencap, 2008).

It is not only the general public and MPs who are confused. Literature searches and reviews are problematic, because of the range of terms used interchangeably which are synonymous with intellectual disability (ID). These include learning difficulty, learning disability, learning impairment, cognitive impairment/disability, mental handicap, mental retardation and (global) developmental delay.

Considering the intellectual heterogeneity of this population, it makes sense to look at ID as a continuum (Holland, 2008). However, even at the profound end of that continuum, there are yet more interchangeable definitions. These include, profound motor and learning disability, profound and multiple learning disability, people with high support needs, people with complex support needs, people with severe learning difficulties, people with severe learning disability, people with severe learning disabilities and / or autistic spectrum disorders and profound intellectual and multiple disabilities.

This does not include all the definitions employed to describe those with additional autism (ASD) effects, which may include (self) injurious and other behavioural support issues (often described as 'challenging behaviour') and general communication impairments, such as mutism or delayed and / or immediate echolalia. Additionally the use of terms to denote severity, or profundity of intellectual disability is interchangeable. One researcher may use the term severe learning disability, yet be referring to an individual who is living independently with minimal support, while another researcher may use the term self advocating when referring to someone who needs full 24 hour a day support and has a key worker advocating on their behalf. There is also international confusion, whereby the use of the term learning disability denotes, for example, in the US, specific educational learning difficulties, such as dyslexia.

1:2 Definitions of Intellectual Disability

This raises the question; what exactly is learning disability? And is this something different to learning difficulty, intellectual disability, intellectual impairment, mental retardation or cognitive impairment? The answer is that all of these terms are currently interchangeable in the UK. This earlier World Health Organization definition, described

'early onset i.e., childhood, along with lowered social / adaptive functioning, in addition to a lower than 70 IQ level' (Global Health Atlas, 2007 p19).

The use of a medical model, succinctly demonstrates that this is not a description of a specific educational learning difficulty such as dyslexia. Those who employ a social model stance, commonly reject this definition.

The later WHO definition avoids IQ measures and includes environmental factors,

'ID means a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a child's health conditions or impairments but also and crucially on the extent to which environmental factors support the child's full participation and inclusion in society. The use of the term intellectual disability in the context of the WHO initiative, 'Better health, better lives', includes children with autism who have intellectual impairments. It also encompasses children who have been placed in institutions because of perceived disabilities or family rejection and who subsequently acquire developmental delays and psychological problems'* (WHO, 2014).

The International Association for the Scientific Study of Intellectual Disability (IASSID) specifies that the term ID,

'encompasses any set of conditions resulting from genetic, neurological, nutritional, social, traumatic or other factors occurring prior to birth, at birth, or during childhood up to the age of brain maturity, that affect intellectual development. These conditions result in a lifetime of lower than average overall capability for self-determination and general independent functioning and performance in vocational, social and personal functions. In some instances these conditions may occur in conjunction with physical, sensory or psychiatric impairments of varying degrees. Such conditions have variable impact on the individual from minimal to severe. They can be compensated for by a variety of interventions, enrichments, training and / or special assistance or supports in all spheres of life' (IASSID, 2001 p5).

The main policy document under scrutiny in this study, Valuing People (DH, 2001) poses the question;

'What is Learning Disability? Valuing People is based on the premise that people with learning disabilities are people first. We focus throughout on what people can do, with support where necessary, rather than on what they cannot do' (p14).

It then proceeds to a definition based on what people cannot do anyway.

'Learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning) which started before adulthood, with a lasting effect on development' (DH. 2001 p14).

This is quite close to the 2001 WHO definition although it is unclear why it has excluded the adaptive functioning element, which is the ability to generalise learnt skills to new situations. According to Williams (2006) in his textbook, written specifically for students studying for social work degrees,

 'Whatever our terminology, an interesting fact is that 'learning difficulty' can't be defined!' (Author's exclamation mark. Williams, 2006, p3)

He then proceeds to an historical discussion of IQ tests and their fallibility around deciding cut off points. If, he argues, the average IQ of the general population is 100 and the UK cut off point is set at 70 this results in a figure of 3% deemed to have ID. However, the majority of this population will never come to the attention of service providers, as they can function very well in wider society. They are employed, married with children and leading 'ordinary lives'. He compares this to surveys of those in receipt of 'learning disability' services, who are later found to have IQ's of more than 70. Using these borderline examples to argue for an inability to define ID is a red herring. After all, IQ measurement (or intellectual functioning) is only one aspect of the diagnosis of ID.

1:3 Profound Intellectual and Multiple Disabilities

The notion posited by People First that *'they wanted to learn and could'* (see p14) is problematic in that it doesn't truly or adequately embrace the full experience of ID. It really only applies to those people whom Williams is describing, i.e. those with borderline or mild to moderate ID. Williams (2006) asks,

'who are people with learning difficulties? (p1) and *'how then can we define a person with learning difficulties'*? (P7)

He acknowledges his attempt is to define what is meant by '*a person with learning difficulties*' but claims '*learning difficulty can't be defined!*' (Williams, 2006, p3) He continues thus.

'*A person with learning difficulties is someone who has social and personal vulnerabilities associated with impairment of cognitive understanding or of learning practical skills, which has existed since childhood*' (Williams, 2006 p7).

Williams rejects this initial definition, by arguing that it is too clinical and also because it attributes the problem to the individual. He proceeds to a definition he believes is more acceptable to social model accounts of disability.

'*A person with learning difficulties is someone who has been labelled as having difficulties in cognitive understanding, but is someone with rights, including the right to maximum control over decisions that affect them, and who may need help and support to claim those rights. A person with learning difficulties is someone whom society identifies as having an impairment in cognitive functioning, but whose needs and interests are not well catered for by societal structures or by the interactions of other people; he or she is a survivor of struggles to overcome this disadvantage, and may need help to continue to do so*' (Williams, 20006 p7).

This rather convoluted definition would arguably be quite difficult for someone with ID to comprehend. His argument also illustrates the narrow, rights based focus of current social model approaches and seems more concerned with establishing the so called constructed nature of intellectual disability by focusing on notions of labelling and societal identification. Both of these claims may well hold resonance with the people referred to as self-advocating, but they are not helpful when trying to establish a discussion about the actual nature of ID. And they do little to illustrate the experience of individuals with PIMD. His later chapter on the social worker's role includes some limited discussion of support for people with '*particular characteristics*' (Williams, 2006 p38), which includes a small section on profound and multiple impairments. Unfortunately it is not very extensive or informative. It merely refers to one way of working, based on an approach called Intensive Interaction. (See, Caldwell, 2006).

Williams' discussion is predominantly focused on those adults who are unlikely to be receiving any LA care services. As Dunning (2010) demonstrated 75% of councils in

England only provide support to adults described as having critical or substantial need. This is in contrast to 2006, when 53% of councils supported those with '*moderate needs and above*' (Dunning, 2010). The people this study is concerned with are individuals with the particular characteristics of profound intellectual impairment with additional sensory and /or physical impairments. They will also be likely to have additional health related difficulties (Harding et al, 2011).

These are not always individuals with a profound motor impairment and a learning disability, which is what the term PMLD originally stood for and which is why there is still some confusion. An individual may have a motor impairment so profound they cannot utilise the muscles necessary to form speech. However, they may have cognitive levels of functioning beyond pre –symbolic and with the right aids and assistance might be able to communicate their '*wishes, views and aspirations*' (DH, 2001 pp 21, 46). An example of this is the painter, poet and author Christie Brown, whose autobiography was made into the film, 'My Left Foot' (Brown, 1998).

However, an individual whose cognitive functioning could be described as pre-symbolic will not express herself or himself using language. Bunning (in Pawlin and Carnaby, 2009) describes the need for a significant other, who will function as their communication partner. She details research, which has demonstrated how difficult it is to ascribe communication intentionality and how easy it can be to interpret behaviours ambiguously which the individual with PIMD cannot then refute (Grove, et al. 2001). She refers also to Fogel (1993) who describes communication as a continuous processing model reliant on the '*active role of the listener*' (Bunning, 2009 p48).

Bunning further describes the need for attunement to individual's behaviour in order to recognize subtle changes in mood, body language, facial expressions, vocalizations or even by accepting or rejecting something within a familiar context. Finally, she refers to Nind and Hewitt (1994) who focus on the need to develop a desire for joint attention. This requires '*observational acuity and response sensitivity amongst communication partners to any behaviour that has the potential to be signal bearers of meaning*' (Bunning, 2009 p57). The greatest increase in this population, more recently, has been in extremely premature babies who survive, but with very profound and multiple challenges (Lacey and Ouvry, 1998, Carpenter, 2000).

The PMLD Network noted this change in demography in their response to Valuing People Now (DH, 2009). They also referred to the lack of recognition of this group including lack of awareness of their specialized support needs (PMLD Network, 2002 p4). Parrot, et al (2008) conducted a local study in Sheffield England, which confirmed these findings (see diagram, Fig.2 p30).

Fig 2:
Numbers of people with a severe/complex learning disability in Sheffield, 1998 to 2008. (Sheffield Case Register June 2008)
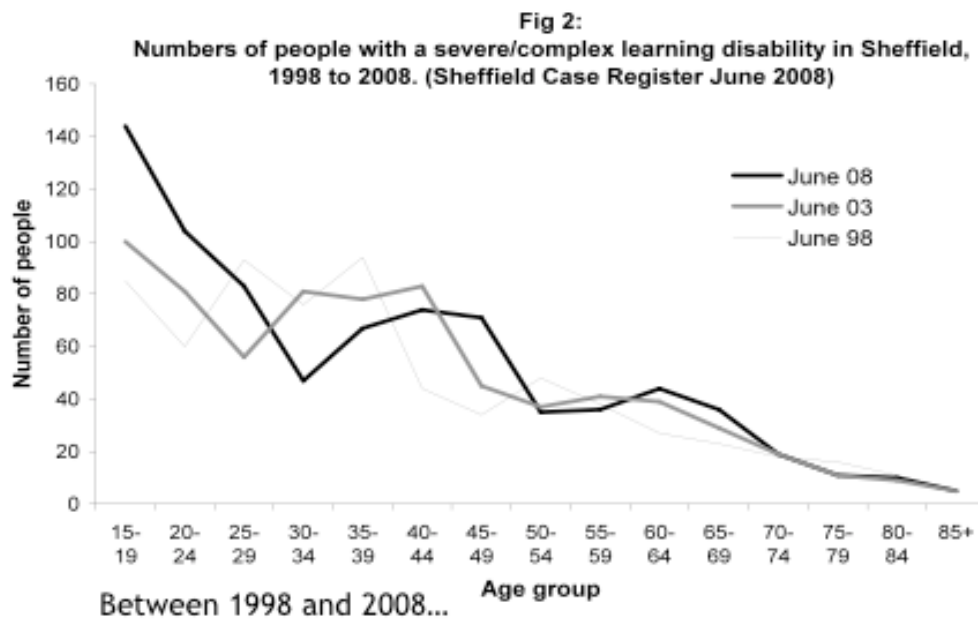
Between 1998 and 2008...
- the overall number of people with severe or complex needs rose by 17% from 682 to 786
- the number of 15 to 19 year olds with severe or complex needs increased by 70% from 85 to 144

As they pointed out these individuals will require lifelong, high levels of specialised support, for all aspects of their daily lives. This will likely include their personal care and continence needs, breathing and airways management, oral feeding (including dysphagia management) and pressure care associated with supporting individuals' with mobility and transfer needs. They will be more likely to have health issues such as epilepsy (requiring medical management) and may have additional recurrent serious health needs requiring hospital admission. They may also have specific degenerative / terminal conditions (Parrot et al, 2008, p30-31). The study further expands on the challenge to primary, acute, community based and palliative care services to strengthen their capacity for meeting these complex needs. Finally, the authors pointed out, their study did not include those adults who may have the additional

behavioural support needs associated with ASD, although the PMLD Network does acknowledge people with specific conditions such as autism or Down's syndrome, may also have profound and multiple impairments. The PMLD Network (undated) have also published a guide, which includes discussion of the physio, hydro and occupational therapeutic input vital to this group's well being.

1:4 Background to the social model of disability

Before examining the impact of the Valuing People policy (DH, 2001, 2009) on the lives of these particular individuals, it is necessary to briefly summarise the framework for services for people with ID in the UK, at the turn of the 21st century. Whilst a historical account of the subject is beyond the scope of this thesis, clearly VP was not published in a policy vacuum. Race (2002) argues that the concept of normalisation has been influencing services for people with ID for well over thirty years. He cites its influence on the 1979 Jay Committee Report's proposed new model of care. It was to be based on three main principles.

'a) Mentally handicapped people have a right to enjoy normal patterns of life within the community.
b) Mentally handicapped people have a right to be treated as individuals.
c) Mentally handicapped people will require additional help from the communities in which they live and from professional services if they are to develop to their maximum potential as individual.' (Race, 2002, p35)

Nirje (1970) first raised the notion of normalisation. He was opposed to institutional living and critical of the prevalent medical model of care. His ideas were aligned to the notion of family type small group living. He summed up his approach, based on the Scandinavian parent movement demands thus,

' making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society' (Nirje, 1970 p19).
These ideas were expanded by Wolfensberger into his 1972 'Principle of Normalization in Human Services' and the later 1975 specific application for 'the severely handicapped'.

His definition described,

*'utilization of means which are culturally normative as possible in order to establish and/or maintain personal behaviors and characteristics which are as culturally normative as possible' (*Wolfensberger, 1972 p28).

His basic principle was later developed into the social role valorization approach (Wolfenberger, 1983a). This emphasized the manner in which people with ID are socially devalued hence his idea that valuing people could reverse this stigmatization. His critics however were concerned that this meant imposing societal norms onto people with ID (Ward 1992, Stainton, 1994).

John O'Brien distilled ideas of normalization into his '*Five Service Accomplishments'* (Concannon, 2005 p78). These consequences of services comprise notions of community presence, relationships with non-disabled people, service user choice, development of competency and respect. O'Brien ran a number of workshops in the UK with Alan Tyne in the l980's and Race (2002) notes

'adherence to' and knowledge of ' O'Brien's 'Five Accomplishments', became commonplace as requirements in job descriptions' (Race, 2002 p196).

Race maintains people conflate normalization, social role valorisation and O'Brien's Five Service accomplishments and further that there are echoes of all approaches in VP (Race, 2002 p43). Chappell (1997) discusses the climate in the 1980's as one where*, 'to criticize it* (normalization) *was tantamount to heresy'* (p47). Yet by the end of that decade the perceived progressive approach to debate, discussion and services for people with ID was losing favour. Bayley (1991) was concerned people with ID were being expected to conform to culturally normative roles rather than an acceptance of their own particular characteristics. Chappell also cites Brown and Smith (1989) and Baxter et al (1990) who highlight the emphasis within the normalization approaches on the perceived value of these roles which people with ID were expected to aspire to. Chappell argues that the social model of disability is a better theoretical framework for discussion, but is also concerned that people with ID '*remain as marginal as ever'* within the social model of disability discussions (Chappell, 1997 p51).

Notwithstanding, the prevailing approach to disability studies in general in the UK is described as the social model (SM). The Office for Disability Issues encourages its use in policymaking (ODI, 2011). This radical new way of understanding disability and disablement emerged from the 'Union of Physically Impaired Against Segregation' (UPIAS, 1975) agenda in the 1970's and gradually evolved into Oliver's (1990) Marxist materialist critique. Prior to this the medical model was the prevailing paradigm (Parsons, 1951) although Shakespeare (2006) notes campaigners and researchers had considered the social aspect of disability issues for some time. Even earlier the eugenics movement were advocating mass sterilization of people with ID. As Mazumdar (1992) points out the widespread debate in the UK at the time led to its opposition. Although the enforced segregation of people in institutions was still actively pursued in order to prevent people with ID reproducing (Mencap 2005).

Disabled activists in the 1970's questioned why they were deemed incapable of functioning in the community. They started to examine the ways society was organized to segregate and exclude them from mainstream participation (Finkelstein, 2004). New ways were sought to represent disability, which moved the focus away from individual tragedy accounts or medicalised labels to issues of policy and planning (Oliver 1990, Barnes 1994). This approach describes environments as the locus of disability rather than the impaired individual. *'Disability is not something we possess but something our society possesses'* (Leaman in Swain et al, 2004, p14). Activists maintained it was the organization of society that needed to change to accommodate the needs of individuals (Oliver, 1990).

UPIAS (1975) members were keen to challenge the underlying causes of disability, as defined by them, rather than railing against its symptoms. From the outset, it was agreed to move the focus of their struggle away from individual effects and towards an examination of the ways society was organised to segregate and exclude disabled people, from full mainstream participation. In order to challenge the existing interpretations of disability they declared a fundamental difference between 'impairment' and 'disability'. According to this new interpretation it wasn't individual impairments that disabled individuals it was societal structures and attitudes. By focussing on societal structures they developed a manifesto framework for fighting this perceived oppression.

'it is the same society which disables people whatever their type, or degree of physical impairment, and therefore there is a single cause within the organisation of society that is responsible for the creation of the disability of physically impaired people. Understanding the cause of disability will enable us to understand the situation of those less affected, as well as helping us to prevent getting lost in the details of the degrees of oppression at the expense of focusing on the essence of the problem' (UPIAS, 1975 p4).

For the purpose of this discussion, it is worth noting that the causes of disability were to be defined by physically disabled people themselves. It is also worth noting the wording of this statement is keen to avoid any discussion of levels of oppression but does explicitly refer to the manner in which the situation of those 'less affected' might be better understood. This detail is key since the body of research currently incorporating a social model approach to discussion of the experience of people with ID, focuses on individuals who are less affected, i.e. have mild to moderate levels of ID (Goodley, 2001, Rapley, 2004).

The overarching concern of the Disability Rights Movement (DRM) in the 1980's was to achieve integration into mainstream employment; in order to alleviate the discrimination and poverty disabled people experienced (Abberley, 1987). In a later paper entitled 'The Significance of Work for the Citizenship of Disabled People' Abberley acknowledges the necessity for a,

'dual strategy of work facilitation for those who want it and can meaningfully take part in the labour process and the general valorisation of non-working lives for those, including impaired people, who are unable to work' (Abberley, 1999 p1).

He argues that a Marxist analysis is useful for understanding the oppression of disabled people in capitalist societies but notes,

'it seems of less use in conceptualising a future for those impaired people unable to work' (Abberley, 1999 p8).

There is a fundamental dichotomy here. The claim to represent all disabled people, in reality meant only those who were able to represent themselves. This was the manner in which the Disability Rights Movement gained prominence in the UK. The raison d'être was about an

individual's right to lead an inclusive life, have a job, live independently and so forth. The primary focus was on the nature and workings of society, rather than on individual impairments. To this end, the early UPIAS debates were concerned with questioning members' socially inferior status. Was this status attributable to embodied impairments, they queried, or to the manner in which society was constructed by people with capabilities, for people with capabilities? And is this why people with impairments are incapable of functioning (Finklestein, 2001).

As Boxhall notes in Race (2002) '*a key aspect of social model theorising is that it has been both authored and controlled by disabled people themselves* (p217). Unfortunately, as Chappell (1998) demonstrated ID was noticeably absent from the discussion and debate.

1:5 Second wave: focus on impairment

Whilst the importance of this new view of disability, cannot be emphasised enough, this new approach did nevertheless present some difficulties. There were those in the Disability Rights Movement (DRM) who questioned the capacity of the model for accommodating the full, lived experience of disabled people. Pinder (1996) argues that separating impairment from disability necessarily misses out the complexity of individuals' lives. It could be argued, that it is this complexity that needs to be grappled with intellectually in attempting a social theoretical approach to understanding the issues. Indeed, Chappell (1998) referred to this emerging discussion and its particular relevance to people with ID. She queried whether the limitations these people experienced could be described as socially or impairment driven. She also suggested it would be helpful if writers were clear about their work, by stating if it was concerned with physical or sensory impairment or disability in general.

The social model approach has been described as an outside – in approach, since the notion of disability is situated in society outside of the individual. As Beresford (2000) points out the social model of disability is solely concerned with the socio/cultural and political aspects of a person's lived experience, rather than individual biological/medical aspects. According to a social model account, it is the conditions, which restrict an individual's life opportunities that need to be identified and analysed. These conditions, it maintains, are bound up in the socio/political sphere rather than within the personal.

Feminist researchers however, with their personal is political agenda, believed lived experience needed to take account of personal embodied issues and argued for accommodating impairment effects by discussing living with constant pain (see Morris, 1991, 1998) or via the production of non-tragedy positive narratives (Crow, 1996, French, 2004). Thomas, (2004) who describes herself as being in the Marxist/materialist camp with the early proponents, later explored the psycho-emotional dimensions of disability, arguing that societal barriers are internally constructed as well as physical. This development could be described as a 2nd wave of the social model. These researchers felt they faced challenges in life, which could not be ameliorated by addressing the social barriers that the early SM proponents identified as constituting disability per se. They could of course demonstrate this, through emancipatory and / or participatory research and these issues could be discussed within a framework of independence and inclusion (see also Goodley, 2004, Hasler, 2003). There is however a contradiction in terms, in attempting to situate the issues associated with PIMD, within a similar framework.

1:6 Post structural perspectives

The current situation is considered by some to be a crisis point for the Disability Rights Movement. Shakespeare (2006) warns against the *'danger of ignoring the problematic reality of biological limitation'* (p49). Chappell et al (2001) refers specifically to the difficulty the social model has with incorporating notions of intellectual impairment. Carlson (2010) has recently discussed the importance of narrative accounts by the families of people with PIMD, whose voice would otherwise not be heard in this arena. She has echoed the concerns of those who felt the parameters of the social model were too restrictive, in that it only truly represented the voices of a fairly small group of disabled activists. There was no analysis initially of congenital and /or degenerative conditions. There was a very strong opposition to the medical model, to the point where there was almost a denial of any need for medical interventions or restrictions.

Davis (2006) describes how newer researchers in the field of disability studies are now looking beyond notions of collective identity. He points to newer assertions around identity, which look at differences between impairments. The question now being asked can one model truly represent the entire spectrum of impairments?

Reviewing the social model approach, Shakespeare (in Davis, 2006) points to three main areas of success; political, instrumental and psychological. Politically, it has enhanced the agenda for social change. There is a clear use of language, i.e. 'people with disabilities', places ownership of the disability with the impaired individual, whereas 'disabled people' implies a political construction of the social origins of disability. By emphasizing the social barriers of oppression and exclusion, rather than a focus on individual deficits, the social model approach was instrumental in the liberation of physically disabled people at least to some extent. This is evidenced by the achievement of accessible buildings and public transport as decreed by the Disability Discrimination Act 1995 (Equality and Human Rights, 2010).

The psychological benefits of the social model approach have been evident in the positive collective identity many disabled people share. Rather than previous representations such as 'in-valid', disabled people have felt greater self-confidence due to participating in mainstream society. However writers such as Thomas and Corker (in Corker and Shakespeare, 2002), Tremain (2006) and Goodley (2011) are now seeking to understand disability via a poststructuralist approach. They are concerned with exploring and deconstructing the binary nature of language, which they argue is an inheritance of enlightenment thinking. They see the Cartesian dualisms at play whereby we can only derive meaning for one term by acknowledging the other (Thomas, 2007).

1:7 Social model and 'learning difficulties'

'*If there is one firm conclusion to be made it is that mild mental retardation is as much or more a social and cultural phenomenon as it is a medical—genetic or cognitive—psychological one. The definition of retardation, then, and some of the consequences of being thus labelled are concomitants of social life'* (Langness and Levine, 1986 p191).

In this slew of research publication and discussion, the subject of this study, i.e. people with PIMD, indeed people with ID in general have received scant attention within the disability movement (see, Chappell, 1998, Chappell et al, 2001, Stevens, 2004). The reason for this could lie with the self – organizing nature of the Disability Rights Movement (DRM) in the UK. The Movement was self-organizing and comprised of physically impaired adults. Their basic philosophy was about agency and about the right to control one's life. Indeed, from the

outset, they saw themselves as a separate group to the 'mentally handicapped' (see Hunt, 1966 p13).

Latterly, in order to better fit the framework of the social model approach, many writers and researchers are keen to discuss the constructed nature of ID. For example, Goodley (2001) claims

'there is a need to work with and for an understanding of 'learning difficulties' as fundamentally social, cultural, political, historical, discursive and relational phenomenon, rather than sensitively recognizing the existence of an individual's 'naturalised impairment' (Goodley, 2001 p210)

Yet all his work is with people whose ID would be located at the very mild end of the continuum. He has acknowledged this *'still leaves a number of individuals unaccounted for by sociological analysis'* (Goodley, 2001 p212). Those unaccounted individuals are the focus of this study.

Numerous books and articles refer to the manner in which the notion of ID came about as a direct result of the enlightenment and the attendant industrial revolution. In the effort to deconstruct notions of intellectual impairment, the existence throughout history of idiots, madmen, fools, and seers has been overlooked (see, Mc Donagh, 2008, Concannon, 2005.) In fact Rapley (2004) even argues it is historically fallacious to try to link those people with people with ID.

The nominal figure of 70 for an IQ definition of ID can of course be considered a construction. However, that is a debate regarding borderline or mild ID. (For further discussion of '*construction of normalcy'* see Davis, 2006, p3.) This thesis is not concerned with that particular debate. Just as the issues across the extensive range of disabilities are different, so too in this area. To argue that the issues to do with mild to moderate ID are the same for PIMD is disingenuous; especially if those with PIMD are noticeably absent from the research literature.

An individual with ID who can use language to communicate can impart their views. They can tell us what they want, what is important in their life, what they might want to achieve or who they want to build relationships with. An individual with PIMD cannot. We must make assumptions about everything to do with their lives. Everything from deciding if they are

thirsty, hungry, bored, tired or in pain to whether or not they would like to listen to music, have a television on, go out to a park, visit a leisure centre in order to go swimming, attend an art class. (This list is far from exhaustive.) Then there are the decisions to do with where they live, what the arrangements are, whom they live with and who provides their support and care. If they do not have family members involved, there will usually be a number of people making decisions for them in their 'Best Interests' (Mental Capacity Act, 2005). Studies have shown those people making the decisions do not always understand the MCA and it implications for people deemed to lack capacity.

*'Those findings reinforce evidence and research elsewhere that there is still a lack of understanding sometimes about how the principles should be used either to support someone to make a decision or how they feed in deciding that an assessment for capacity may be necessary' (*Williams et al*, 2012 p 112*).

1:8 Social model and PIMD

Shakespeare (2006) queries how it can be possible to create a barrier free society for people with ID, or for those who are on the autistic spectrum or who have profound visual impairments? The questions this study is exploring hone in on those people who may well have all of these impairments and more besides. How can it be possible to accommodate all of their impairments effects within a simplistic rights based approach? The right to work, the right to own one's own home, the right to marry and have children are all synonymous with ideas about inclusion in a barrier free society. However, this argument is based on a fairly restrictive view of society. Not everyone believes self worth and identity only come from paid employment, marriage, children and a mortgage. There is no counterbalance to this and no recognition that for some people, *'those whose needs are profound, multiple or complex, paid employment will be an impossible aspiration'* (Johnsson et al, 2010 p78)

Recently there have been attempts to find ways to include people with PIMD in participatory research, in line with a social model approach. (Concannon, 2005, Boxhall, 2010, Whait, 2011) The difficulties they have all encountered will form a part of the later discussion.

1:9 Beyond the social model

Hughes and Paterson (2004) have suggested a theory or sociology of impairment is needed. They believe disabled people experience impairment and disability

'not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction' (Hughs and Paterson, 2004 p69).

They believe phenomenology is the best way to encompass an understanding of *'lived experience' as … 'embodied (the body with mindful agency) and social'* (Hughs and Paterson, 2004 p129).

The effects of other binary divides analysed by post-structuralist writers have also been explored by psychoanalytic writers. Marks (cited in Thomas 2007, p66) has researched professional care workers' projected defences, which Menzies (1960) also detailed in a study of nursing in a UK general hospital.

The critical realist perspective accommodates complexity and avoids cultural, economic and biological reductionism (Shakespeare, 2006). This perspective also acknowledges the universality of impairment albeit with much variability over the life course and from one individual to another. This perspective acknowledges *'And of course, some disabled people are entirely unable to work'* (Shakespeare, 2006 p66).

Kittay (cited in Carlson, 2010, p89) states categorically, in the case of her daughter, it is not society rather it is her profound impairments, which restrict her life (p89). The difficulty with the social model is that it purports to represent the entire spectrum of disability. This was always going to be problematic. Especially when considering those individuals who could never live independently, be employed or indeed live a wholly inclusive life. These people have not featured in much of the ongoing discussion and debate, by dint of the nature of their impairment.

It is the aim of this study to disentangle policy from philosophy. When Valuing People (DH, 2001) re-conceptualised ideas of intellectual impairment via a unified approach within a framework of independent living and employment for all, it was not taking into account those

individuals with the most complex and challenging support needs. Perhaps it was an attempt to assuage the fears of politicians concerned by the burden of their unproductiveness (Concannon, 2006). After all, if it is claimed that everyone has the potential for employment, there is no need to consider the supposed burden of lifelong dependency.

In the ongoing reform of the welfare system, notions of dependency are being replaced by ideas of individual responsibility and active citizenship. Valuing People Now (2009) clearly states that rights come with responsibilities (p14). As Powell (1999) points out, the state confers rights and in recognition the active citizen must take individual responsibility and participate in the labour market. Unfortunately, this holds little relevance for individuals with PIMD, although there are some who maintain this is a valid route (see Darwent, 2012). There is however, no mention of the right to social welfare provision (Dean, 2002) or the right to local specialist day centre provision, or to local specialist college provision. Neither is there any mention of the right to trained support workers or to the range of specialist support, such as physiotherapy, occupational therapy, speech and language therapy, and psychological support, which the strategy acknowledges, as being key to good outcomes for this group.

Redley and Weinberg (2007) point out the inherent contradiction, in recognising ability over disability and in promoting people's political empowerment and voice in the design of public services. To what extent, they ask, can people with ID be empowered by a citizenship model, which in itself requires intellectual ability and independence? Their query is even more pertinent when considering those individuals with PIMD.

The increasing influence of this rights based approach has been criticized for ignoring the realities of PIMD (Chappell, 1998, Gilbert, 2003, Mansell, 2006 and Shakespeare, 2006). The lack of clear definitions for people with PIMD has been criticized (Samuel and Pritchard, 2001). Carnaby (2004) has discussed the unique nature of individual's lived experience and the impact on their supporters. He points out that this makes large-scale empirical studies problematic since they cannot account for the idiosyncratic nature of PIMD itself. His review of research about the lives of people with PIMD questions the VP philosophy of social inclusion and integration for this population, especially when considering their specialist health and support needs (p24-25).

This clearly demonstrates the rationale for a research study, which interpretively explores the impact of the VP agenda of rights, independence, choice and inclusion on the lives of people with PIMD. The use of a triangulated design affords the opportunity to gain input from the unique perspectives of the family and care workers, who have the most day-to- day contact with and understanding of this population. Utilizing a critical realist stance will make it possible to analyse the underlying philosophical approaches, whilst maintaining a clear understanding of the lived reality of PIMD.

The following chapter will review and evaluate the literature with particular regard to the subject of PIMD. This will provide an overview and context for the ensuing research and discussion by revealing the gaps in the literature. In particular with regard to clarity of definition of PIMD, a general lack of understanding of the complexity of needs associated with PIMD, the lack of representation of people with PIMD in government policy and finally the lack of fit with current approaches, which it will be argued impacts negatively of provision and delivery of appropriate and specialist services.

Chapter 2   Literature Review

2.0 Introduction

This review assesses the literature, as it pertains to profound intellectual and multiple disabilities (PIMD). This includes papers, which discuss issues with terminology and definitions associated with ID, stakeholder responses to the publication of Valuing People (DH, 2001) and Valuing People Now (DH, 2009) and studies, which refer to the rise in numbers of individuals with PIMD. The review examines the social model approach to intellectual disability (ID) with a critical appraisal of its relevance to PIMD. This in turn leads to an exploration of the place of PIMD in current policy, including policy makers' awareness and understanding of the subject (Bourdieu, 2005). The latter section assesses the literature, with regard to the cornerstones of Valuing People (DH, 2001) i.e. rights, independence, choice and inclusion and finally there is a section looking at post-social model (SM) discussions. This summary of relevant published work will provide the background context for an exploration of the VP journey from policy to practice and the inherent difficulties this has for a particular group of individuals and those who provide their care and support.

The original Valuing People white paper was published by the Department of Health in 2001. It heralded a supposed paradigmatic shift in the way people with intellectual disabilities (ID) would be viewed in the future. No more marginalized or excluded, they were to be offered '*life opportunities*' (DH, 2001 p1) which would see them leading '*full and active lives*' (DH 2001 p1). The overarching aim of Valuing People was sub-titled as 'A New Strategy for Learning Disability in the 21st Century' (DH, 2001). A key concern for this thesis was how the new policy direction impacted on the lives of adults with profound intellectual and multiple disabilities (PIMD).

The search was conducted at various research libraries including the Kings Fund, the British Library, Middlesex University and also included online searches through various Journals, including Disability & Society, Journal of Policy and Practice in Intellectual Disabilities, Critical Social Policy, Tizard Learning Disability Review, British Journal of Learning Disabilities and Journal of Intellectual and Developmental Disability.

Search terms included Learning Disability/Difficulties, (LD), Severe Learning Disability/Difficulties (SLD), Profound and Multiple Learning Disabilities (PMLD), Intellectual Impairment/Disability (ID), Profound Intellectual and Multiple Impairments (PIMD), Complex Needs (CS), High Support Needs (HSN). All these terms have been used by writers in the various journals listed above to refer to individuals with PIMD. Additional terms used within VP (DH, 2001) included, *'people with additional or complex needs'* (p90), *people with severe learning disabilities and complex needs'* (p11), *'severe and profound learning disabilities '* (p15), *people with complex and multiple disabilities'* (p16), *'the most severely disabled''* (p21),*'those with severe disabilities'* (p52) *'severe and profound disabilities (including those with sensory problems)'* (p100). The later VP Now refresher document (DH, 2009) includes '*People with more complex needs'* (p2), '*severe and profound learning disability'* (p20), '*severe or profound learning disabilities and/or autism'* (p30) and '*profound and multiple learning disabilities'* (p34).

2.1 Rationale

The thesis is seeking to evaluate the philosophical context for policy in the area of ID, commencing with the publication of VP in 2001. The rationale behind this is a perceived mismatch between the ideological approaches informing government policy and the lived experience of those individuals with PIMD, which has also been noted by Dawkins (2009) and Pawlyn and Carnaby (2009).

This Literature Review was conducted, in order to analyse peer reviewed papers, published books and documentary articles, including those which sought to unpick the effects of the VP policy over recent years. The need to include non-peer reviewed articles arose since it was felt important to have at least some representation of the voice of people with ID themselves (Walmsley, 2001) especially since it is impossible to include the views of individuals with PIMD (Docherty et al 2005, Bochel et al 2008).

Since VP was published in 2001, there have been a number of refresher documents, such as VP into Employment (DH, 2008) and VP Now (DH, 2009). There have also been a number of studies conducted, which were recommended and promised within the original strategy (Emerson and Hatton 2008, Emerson 2009). None of these acknowledge the difficulties inherent in representing the experience of those with PIMD.

One researcher has tried.

'…every effort had been made to include those who found spoken language difficult or impossible. However, despite adopting some of the strategies advocated by social psychologists to aid communication, and many attempts at rephrasing simple sentences, few of the interviews with those with little or no verbal communication were successful. Indeed the exercise suggested that social psychologists who make substantial claims for the possibility of communication with such people, seriously underestimate the problems involved for anyone without extensive knowledge of the individual concerned.' (Concannon, 2005, p172).

In this account of a research study, exploring the ways adults with ID were included in service planning, Concannon has acknowledged the extreme difficulties involved in trying to include those with PIMD. Whilst his study included adults with a range of ID, this thesis is focusing entirely on those individuals with PIMD. Hence, Concannnon's conclusion that his study demonstrated, '*the need to change the approach to practice and policy development* ', has even more resonance for this investigation. Especially, as ' *It suggests that the agenda is not whether people share the same view, but that their differences are acknowledged and included in the process*' (Concannon, 2005 p171).

The published literature in the field of ID is growing although Digby (1996) compares the academic marginality of the field of learning disabilities research with the social marginality of people with ID themselves. Mc Conkey (1998) refers to the heterogeneity of this population and difficulties with definitions, which makes generalizing from findings problematic. Hamilton-Kirkwood et al's (2001) review of the literature commences by appealing for

'*a common terminology*' and suggests that '*some authors propose a more innovative exploration of the potential of the multi-dimensional framework of ICIDH-2*' (Hamilton-Kirkwood, 2001 p5).

This review includes many studies, which focus primarily on individuals with PIMD, however they are mainly exploring the efficacy of various medications or therapeutic interventions designed to ameliorate behaviours described as challenging (Hamilton-

Kirkwood, 2001 p20). PIMD specific research is scant. This is no doubt due, in part, to the difficulty Concannon has described, in attempting to involve individuals via the currently preferred social model research methodologies. Emancipatory and / or participative approaches, in which

'*the aim is to draw disabled people into the process of designing, conducting and disseminating disability research*' (Barnes and Mercer, 2010, p 33)

have obvious difficulties for research with this demographic. Some researchers have attempted to find ways to include this population in a participatory fashion. Boxhall (2010) has published a paper outlining ' … *the benefits of involving people with profound and multiple learning disabilities in research*' (Boxhall, 2010 p173).

Boxhall uses Millsian cost/benefit analysis to describe the unforeseen benefits, which might accompany creative methodological approaches. The Renton Foundation completed a three year research partnership with Mencap and the British Institute of Learning Disabilities, called Involve Me (Whait, 2011). The aim of the project was to increase the involvement of people with PIMD in decision-making and consultation. To date, no follow up review has been conducted to assess the efficacy of this approach.

2.2 PIMD: minority within a minority

A key contention of this study is that, the confusion around terminology is not helped by a perceived unwillingness to acknowledge profundity and multiplicity of impairments, when associated with ID. This thesis will contend that this is due to the application of social model approaches, which in the case of some post structural writers, actually deny the biological and at the most extreme, state that these (perceived as negative) biological assumptions, are socially constructed (Williams 2006, Goodley, 2001).

In a paper discussing classification in the UK and abroad, Leyin (2010) describes the binary system in use in the UK. This simply categorises intellectual impairment as either learning disability or severe learning disability and uses the IQ figure of 50-55 as the indicator of severe learning disability (SLD). This is in contrast with international, four part classifications, which sub categorises into mild, moderate, severe and profound.

The international classification for SLD is an IQ measure of 35. Leyin points out that this has led to a good deal of confusion, especially in the area of research and epidemiological studies. Researchers do not always state which classification they are referring to when they describe SLD. He describes the use of this terminology within Valuing People (DH, 2001) as

'*a hybrid system that uses the terminology of the international system but in a way that relates epidemiologically, to the national system*' (Leyin, 2010 p37).

His contention is that this confusion must necessarily impact on service provision, since these estimates are what inform service provision in the first place.

This confusion around terminology is compounded by the current use of levels of support measurements replacing the previous levels of impairment. Davidson (in Leyin 2010) warns against adopting a purely socio/adaptive measure, since this form of assessment is less reliable, poorly defined and standardised on biased norms. He argues the intellectual impairment criteria offer greater objectivity and

'*the existing thresholds are less likely to be moved as a result of political considerations such as fluctuations in the availability of resources*' (p43).

This appears to be happening. Families interviewed for this thesis reported that the Fair Access to Care (FACS) criteria had been adjusted by their local authority, from critical to substantial for many service users. Since families were providing informal support it was claimed the individual's overall needs were no longer critical. This is the subject of much debate and legal enquiry. It has not been resolved to date (Hoult, 2011, Butler, 2011).

The VP commitment to improve the national information data resulted in Emerson et al (2005) and eventually, specifically to Emerson (2009). Presumably it was recognized, that in the slew of government research referred to (130 Projects, completed around 2001, plus another £3million on 50 studies commencing in 2001(Emerson, et al, 2005 p115) the issue of PIMD had been overlooked. A search of the National Research Register archive resulted in 1 piece of research (Remington 1997).

The ambitious joint report, (its own description) '*Improving the Life Chances of Disabled People'* (DWP et al, 2005) was published by the (now defunct) Prime Minister's Strategy Unit (PMSU). It was prepared with a number of government departments including the Department for Work and Pensions (DWP), Department for Education and Skills (DES), Department of Health (DH) and also by the Office of the Deputy Prime Minister (ODPM). With such a wide - ranging remit (i.e. all disabled people) it is perhaps understandable that people with PIMD were not acknowledged as a distinct group, with particular challenges and barriers to accessing '*the opportunity society' (DWP et al, 2005 p7)* and '*helping themselves'* (DWP et al, 2005 p7). However, considering the study comprised three distinct phases, including an extended scoping exercise, an analytical phase and a policy recommendation phase, it is unclear why PIMD was so overlooked.

The F Annexe to the report, 'Improving the Life Chances of Disabled People with the Most Complex Needs' (PMSU, 2005, includes the results of a literature review of '*specific issues faced by disabled people with the most complex needs'* (DWP et al, 2005, Annexe F p31). Here, though, '*complex needs'*, include mental health issues combined with drug and alcohol dependency and associated homelessness.

The Summary states, '*… there are in fact other groups about whom there is no research at all'* (DWP et al, 2005 Annexe F p31)

and later in section 1.2.2 entitled '*People with learning disabilities, high support and multiple needs"* (DWP et al, 2005 Annexe F p41),

' *A key issue for service provision and support is the lack of information about the numbers of people with high support needs. The current lack of information means their needs are not always taken into account when planning or commissioning services'* (DWP, et al 2005 Annexe F p42).

The successor to this report has avoided any mention of people with PIMD at all. Considering the report '*Fulfilling potential Building a deeper understanding of disability in the UK today'* (DWP, et al 2013) outlines its aims to raise awareness, increase public understanding and prompt debate around disability issues, this seems an unfortunate lost opportunity. The section dealing with '*building an understanding'* (DWP et al, 2013 p10) for example, refers

to secondary health conditions, but merely mentions at the end of the section that *'people with learning disability are less likely to feel confident about managing their conditions themselves'* (DWP et al, 2013 p12). This provides no insight into the complex, varied and multiple health issues associated with people with PIMD.

A later section (DWP et al, 2013 p31-55), purports to demonstrate an understanding of the lives of disabled children, yet provides no reference to the studies, which have demonstrated a rise in numbers of children with profound and complex disabilities (for e.g. Parrot, 2008). Indeed there is no acknowledgement whatsoever of children with PIMD. And yet, Emerson et al completed their study estimating future numbers of adults with PIMD in 2009. They concluded there was evidence of a *'sustained and accelerating growth in* numbers' (Emerson, et al, 2009 p7). The annual increase was estimated at 1.4% rising to 3.2% in 2026.These estimates were based on data and a set of assumptions. According to Emerson, there was an inherent difficulty in basing estimates on future mortality rates; however the overall pattern of predictions remains consistent when these are varied.

The smaller scale study, looking at changes in demography and demand for services from people with complex, profound and multiple needs, in the city of Sheffield, fed into the Emerson report and also gave some indication of the urgency for acknowledging the predicted future rise in need. This report (Parrot et al, 2008) analysed and then demonstrated the change in overall numbers of people with ID, including further analysis of the health and support needs of young people (i.e. 16-19 years) in Sheffield (Parrot et al, 2008 p29). It concluded that there was a 120% increase in number of children/young people with ID (p29) and a further 70% increase in young people with severe/complex needs (p29) Accordingly, demand in Sheffield is described in this report, as *'outstripping available resources and the gap will continue to grow'* (p26).

This very detailed analysis of support and health needs includes the current population and the predicted population for a range of age groups. As with Emerson (2009) it recognizes the need to refine projections, by developing more accurate modelling of likely future changes. This report has tried very hard to accommodate the full range of people with profound and multiple needs, however it recognizes that those individuals with complex and severe health and support needs are not included here, but they are also people who will need effective health and support throughout their adult lives.

Jo Williams (2008) then CEO of Mencap and Co-Chair of the Learning Disability Coalition, responded to the Parrot report thus,

'The Sheffield report has been widely used to demonstrate that social care in England is grossly underfunded.' She goes on, *'Parrot's article gives us a vivid description of the overwhelming need for multi-agency co-ordination between primary, secondary and acute health services and social care (Williams, 2008* p37).

She outlines the need for more accurate information about numbers of people with ID and PIMD, the need for an evaluation of the demographic, social and economic trends affecting demand for services, including their cost and to know what savings can be made from existing funding (Williams, 2008 p37). It is unclear why all of this did not happen before the policy of Valuing People was devised and published.

In an interview with Andrew Holman (2001) Rob Grieg, the author of VP pointed out, the strategy development for VP was achieved completely in eighteen months. Perhaps with hindsight, it is now clearer that more time ought to have been spent auditing current services and current and future need, including an analysis of the demographic. In the words of Samuel and Pritchard (2001)

'if we do not know who we are talking about, how can we possibly know what the issues are?' (Samuel and Pritchard, 2001 p34).

Tellingly Samuel and Pritchard used the title of their paper to refer to this group of people as *'the ignored minority'* (Samuel and Pritchard, 2001, p34).

Since VP was heralded as *'the first government statement about the lives of people with learning disabilities for thirty years'* (Grieg, 2005, p3) it is perhaps timely to note what the previous white paper had set out to achieve. 'Better Services for the Mentally Handicapped' (DHSS et al, 1971) aimed to close hospital places and increase local authority residential places via the model of care in the community. A few years later the Jay report (1979) recommended this provision, ought to be geographically local to where people had been born and/or spent their early childhood. However the report was concerned that *'certain mentally handicapped people have a temporary or permanent need for specialized skills because of the*

nature of their handicap (Jay, 1979 p97). Samuel and Pritchard might also query if we knew in the 1970's that there were certain people with specialist needs, why did we overlook them in such a major piece of policy in 2001?

Cramp (2003) describes himself as a, '*self - advocate and Mencap trustee with a learning disability' (p18).* He has written a paper, which explores the idea that the promises of Valuing People (DH, 2001) were likely to be undermined by underfunding and tokenism. He questions whether the £12 per head/per annum (based on Government figures of £16.7m for approx. 1.5 million people) is really likely to bring about radical change. Especially since Mencap suggests £300million per annum is needed to bring about the changes envisaged by VP (Williams, 2008).

Cramp (2003) also points out that without the services of an advocate, the policy objectives of '*increased choice and control over their lives were empty rhetoric for many people'* (Cramp, 2003 p20)

and further,

'*The emerging picture at present seems to be one of very limited progress within a grand vision of change funded by meagre resources.' (Cramp, 2003 p21)* and finally,

'*The White Paper was an important step from the government, but without more funds and more priority on improving services, there is a danger that Partnership Boards are just talking shops and that Valuing People will have no real impact on the lives of people with a learning disability*' *(Cramp, 2003 p21).*

Considering he is discussing the strategy in terms of delivery for all people with ID, it is clear that those who make up the smallest minority within this population, i.e. those with PIMD are likely to be overlooked or ignored as has been suggested (Samuel and Pritchard, 2001).

In a review of the implementation of the VP policy, Cumela (2008) criticised the Department of Health's annual learning disability reports (e.g. DH, 2005) for resembling '*promotional literature rather than performance monitoring'* (Cumela, 2008 p178). The author outlines concerns, particularly in the area of '*person-centred assessments as a means of enhancing*

choice' (p183), which '*have probably affected only a minority of those eligible, and may have differentially excluded the most disabled*' (Cumela, 2008 p183).

A London wide consultation was carried out during 1999, prior to publication of Valuing People in 2001, on behalf of the NHS Executive and Social Services Inspectorate. The mapping exercise, entitled Vision and Values (NHS Executive et al, 1999) demonstrated what was happening with services in London, in particular, via the modernization agenda. It was incorporated into VP; evidenced by the themes of choice, control, inclusion and partnership working. It also stated very clearly, that it was working from a social model of disability perspective (Grant and Ramcharan, 2008). However, it also recognized, that achieving the vision for individuals with higher health and social care support needs,

'*requires greater skill, greater co-ordination, more ingenuity, sensitivity, persistence, patience and strong team working*' (NHS Executive et al, 1999 p 46).

Unfortunately, as Mansell (2010) has pointed out this is still mostly done by the families (i.e. unpaid carers). The London wide consultation for Vision and Values (NHS Executive, et al, 1999) included families, people with an ID, frontline workers and managers and service providers from all sectors. Considering this wealth of expertise about what the real issues and needs were, it would have seemed appropriate to accommodate the recommendations for respite and bases into the new VP strategy, but neither were. With the rolling out of personalization, individuals with a personal budget (see Needham in Glasby, 2011, p37) may not be accessing conventional day centres as much as in the past, if at all. Whilst these people are accessing various activities in their local community they need somewhere to base themselves. Mansell (2010) has referred to these so-called bases in his report 'Raising Our Sights'.

'*local authorities should ensure they continue to provide somewhere which can be used as a* base *from which adults with PIMD can go to different activities during the day. This does not have to be restricted to people with PIMD - a place used by a wider range of people might be more interesting and provide more opportunity for social interaction*' (Mansell, 2010, p29).

There is an ongoing philosophical tension at play at play here. On the one hand day centres are depicted as segregated colonies, which need to be closed down (Holman 2001, Williams

2006, Goodley 2004). On the other hand, those with knowledge of this demographic (i.e. adults with PIMD) are aware of the ongoing need for some dedicated space away from the family or residential care home. Somewhere individuals might experience stimulating activities combined with structured ongoing health and care supports, such as occupational therapy, speech and language therapy, physiotherapy and psychological / behavioural support programmes (Henley, 2005). VP simply envisioned people accessing these therapies through mainstream health services and suggest individuals use the proviso of reasonable adjustments to ensure a service (EHRC, 2011).

Valuing People Now (2009) does appear to have finally recognised that work for all is not entirely possible. It states,

'*it has to be recognized, that for some people with highly complex needs, such as those with profound and multiple learning disabilities or who are medically dependent, paid employment poses particular challenges, although it remains an aspiration'* (DH, 2009 p59).

The latter part of this statement is rather puzzling as it is not clear whose aspiration the writers are referring to. This is an important point. If people who understand the real lived experience of PIMD persist in confusing the issues with statements that over ascribe intellectual capacity, it will always be difficult to convince policy makers otherwise.

The difficulty with being a minority within a minority is made clear in Williams (2006). This is a textbook is specifically written for social work degree students and focuses on post VP aims for services for those with ID. There is little discussion of PIMD, apart from a short description of a style of interactive work, called Intensive Interaction (Williams, 2006 p38, pp120-121). There is some discussion of alternative communication, whereby the author contends that for many people with severe communication difficulties, estimated at 50-90% of all adults with ID, it is more to do with '*our difficulty in understanding'* (Williams, 2006 p120). This is arguably disingenuous. It is a '*brute fact'* (Kristiansen, et al 2010, pp47-49) that an individual with severe to profound ID, will be at a very early developmental stage. This is also discussed at length by Bexley 2002, Kelly 2000, Garcia and De Haven 1974 and Blunden et al 2000) The authentic stance would be to acknowledge we can only ever make assumptions or presumptions about an individual's preferences based on detailed background knowledge, observations and by developing a relationship with said individual over time. This discussion will be explored more fully in the later section on choice.

2.3 PIMD and the Social Model

The difficulty with devising a model, which was originally focused on the right to work, arises, when people latterly try to make the model all-inclusive. That is, purporting to speak for all. UPIAS (Finkelstein and Davis, 1997) makes numerous references to

'*our exclusion from the ability to earn an income on a par with our able-bodied peers'* (Finkelstein& Davis, 1997 p1).

'*to struggle for changes to the organisation of society so that employment and full social participation are made accessible to all people'* (Finkelstein and Davis, 1997 p2).

'*to go forward with the serious struggle for the right to paid, integrated employment'* (Finkelstein and Davis, 1997 p5).

'*integration into ordinary employment. This is the fundamental principle by which schemes for meeting the financial and other needs of disabled people can be judged'* (Finkelstein and Davis, 1997 p6).

'*dependence on the State must increasingly give way to the provision of help so that a living can be earned through employment'* (Finkelstein and Davis, 1997 p8) and

'y*et the struggle to achieve integration into ordinary employment is the most vital part of the struggle'* (Finkelstein and Davis, 1997 p11).

This list is not exhaustive but it illustrates the prominence of this aspect in the very early discussions. Oliver (2004) refers to

' *…disabled people's agenda that focuses on issues such as employment and social inclusion, independent living and civil rights'* (Oliver, 2004 p23) and believes that there is a need for

'*…adopting a firm target and formulating appropriate plans for the employment of disabled people'* (Oliver, 2004 p24).

As Tremain (2006) points out though,

'Identities of the subject of the social model can therefore be expected to proliferate, splinter and collide with increasing frequency as individualizing and totalizing diagnostic and juridical categories offer ever more finely tuned distinctions between and varieties of (for instance) congenital and acquired impairments, physical, sensory, cognitive, language and speech impairments, mental illnesses, chronic illnesses and environmental illnesses, aphasia, dysphasia, dysplasia and dysarthria, immune deficiency syndromes, attention deficit disorder, attention deficit hyperactivity disorders and autism' (Tremain, 2006 pp193-194).

As she rightly points out, an identity based movement will eventually be challenged for excluding someone or group. This is what has happened with ID and of course PIMD.

As Morris (1991) put it,

'there is a tendency within the social model of disability to deny the experience of our own bodies insisting that our physical differences and restrictions are entirely socially created' *(Morris, 1991 p35).*

'...to suggest that this is all there is to it, is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying' (Morris, 1991 p35).

Indeed, Rapley (2004) argues from a discursive psychological perspective that rather than ID being a tangible, internal, individual thing, it is an interactional product. The identity of ID, he argues, is constructed through moment-by-moment social interactions with others. (Usually care staff or professional, although oddly he does not mention families.)

He further argues, that the range of diagnostic definitions which have been employed since the 1800's, have furnished *'the appearance …… of an homogenous disorder, where in practice there is heterogeneity, diversity and uniqueness'* (Rapley, 2004 p197).

He refutes the 2nd wave social model writers who, he argues, need to re examine their acceptance of the proposition that ID is an essentialised, interiorised and real impairment (Rapley, 2004 p201). In essence his argument distils down to a refutation of the original

Weschler (1981) IQ tests. Granted (in)competence may well be negotiated and constructed locally, as he argues '*for local purposes, by local means*' (Weschler, 1981 p202). However by focusing on individuals who can self-advocate, Rapley has restricted his own argument. He argues against acknowledging internal mental attributes that may constrain an individual's capacity (Rapley, 2004 p202).

He argues further that '*to theorise ID as such is to confer solidity and permanence on that which is nothing but a habit of speech, an hypothetical construct which homogenizes and totalizes that which it's proclaimers promise to pick apart*' (Rapley, 2004 p205).

By focusing entirely on the mild to moderate end of the spectrum, he is denying the existence and validity of PIMD. At least the SM researchers and writers described as second wave, attempted to include the vast range of diverse human experience that is encompassed by all persons including those with ID (eg, French and Swain, 2004, Thomas, 2001). Rapley concludes his argument by querying if all we have done is reformulate scientifically the moral defective classification of the feebleminded?

It is unclear how these writers can make global claims about ID, such as its socially constructed nature when they only focus their research at the mild end of the ID spectrum. This author argues their reason for doing so is to fit their own theory. If they were to open out the discussion to include the entire gamut of the ID experience they may find their theorising is not as neat as it seemed.

Goodley (2001, 2011) and Goodley and Rapley (2001) have challenged the existing medical definition of ID. Goodley queries why, epistemologically,

'*some elements of humanity are open to sociological investigation (MLD), whilst some are left in the realm of static, irreversible, individualised biology (SLD)*' (Goodley, 2001 p226)

Perhaps, if Goodley did some research in the field of PIMD, he would revise his own assumptions. The difficulty with Goodley (including 2011) and the few others who have attempted to include discussion of ID within a SM approach, is that they focus exclusively on individuals who can self advocate and who certainly experience very low level impairment effects, as a result of their (socially constructed?) MID. These are the people Bogdan &

Taylor (1982), Langness and Levine (1986) and Dudley-Marling (2004) describe. In fact, Simone Aspis (2004) whom Goodley often quotes was interviewed about her work on her MA in Ethics and Law.

In much the same way as the feminist second wave, disability activists reintroduced an embodied ontology to disability studies, via their own political agenda of the personal is political some researchers began to recognize that those with ID were absent from the whole disability debate (Shakespeare, 2006).

The March 2011 editorial of the British Journal of Learning Disabilities, called for '*papers that are written by people with learning disabilities, on their own, or in partnership with other researchers*' (Mitchell, 2011 p1). Surely this further marginalizes those individuals with more profound intellectual impairment effects? Again, it is not clear whether or not Mitchell believes individuals with PIMD can effectively produce academic research '*in partnership with other researchers' (Mitchell, 2011* p1) or if he is simply using what he believes to be social model friendly language. Emails to clarify this were unanswered.

Armstrong (2002) discusses self-advocacy as '*a policy option through which the citizenship of people with learning difficulties can be asserted*' (Armstrong, 2002 p334). In order to do this he argues, the starting point must be a rejection of biological assumptions. Here is another writer who uses language, which ostensibly creates the impression, that all people with intellectual impairment have the capacity to truly self-advocate. He talks about eliciting perspective when in reality he is discussing very keen observation of an individual with PIMD. He describes the

'*…ways in which people with severe and profound intellectual impairments can be listened to, using behavioural and subtle communication cues, in addition to, or instead of, conventional or gestural forms of communication* (Armstrong, 2002 p340).

He must then make assumptions about what he believes the individual may be feeling. He may well arrive at a completely different conclusion to somebody else, as this is such a subjective endeavour. This is not the same as an individual providing their views first hand. More recently Darwent (2012) has published an article entitled, 'Quietly Confident', in the Mencap magazine Viewpoint. Whilst the writer initially points out that the subject of the

article is a man with PIMD who cannot communicate verbally, she proceeds to describe his new life as a college lecturer and trainer. The use of language such as

'*he set up, he addressed, he advised, he planned, wrote and delivered the course*' (Darwent, 2012 p20-21),

conveys the idea of an involved, proactive, cognizant individual. The article is a good news story, which manages to focus on the notion that employment has turned his life around. The article points out that

'*..he was enjoying a social life, he loves going to the pub and eating out, but something was missing* ' (Darwent, 2012 p20).

It is unclear why his support team could not devise more meaningful, structured or therapeutic activities, rather than make his activities fit the quasi role of so-called employment. (So called, as it has been impossible to determine if he is actually paid for his work.) This thesis challenges the VP assumption that in order to have value an individual must fulfil society's normative roles.

Emails to the author of the article for further elucidation remained unanswered and attempts to contact the social work lecturer (Darwent, 2012 p21) failed also.

According to the World Health Organisation (2011) definition ID includes,

' *a state of arrested or incomplete development of mind, i.e. significant impairment of intellectual and social /adaptive functioning and presenting since childhood* '.

There is further discussion of the manner and difficulties inherent in measuring significant impairment. There is also discussion of the need to take into account an individual's personal circumstances, such as age, gender and religion, when assessing social functioning. And there is a comprehensive overview of the various legal definitions used in the UK for ID. However, nowhere, is there any mention of ID as socially and culturally constructed.

Coles (2001) conducted a small-scale interpretative research study in order to examine whether or not social model approaches to disability were informing service practice and delivery for people with profound and complex ID. The tone of this paper is highly subjective and the researcher makes quite inflammatory statements with no accompanying evidence. For example,

' *those categorized as having profound and complex learning difficulties have been particularly vulnerable to the awful practices that medical model thinking spawns*' (Coles, 2001 p502).

His simplistic analysis of good practice (social model) vs. bad practice (medical model) is challenged by Shakespeare (2006). Indeed for Coles, the paradox arises, whereby he encounters a support worker who knows nothing of the social model of disability yet surprisingly (for Coles) appears to treat his client with respect, promotes his human rights and sees his client as a person not a diagnosis. As Shakespeare points out, particularly in the area of ID, other social contextual approaches, such as normalization (Nirje 1980) social role valorization (Wolfensberger 1989) and particularly in the UK, O'Brien's Five Service Principles (1987) with their emphasis on de-institutionalisation and human rights, signalled similar values and objectives to SM approaches.

2.4 PIMD and Policy

'*The right hand of the state does not know what the left hand is doing*'. *In other words policy makers have no knowledge about the work of those people who implement their policy. Hence, 'the knowledge of what is really going on in society is not shared with decision makers, who in turn do not acknowledge the specific character of socio-professional work*' (Bourdieu in Duyvendak 2005, p7).

When Valuing People was published in 2001, it included a Foreword by the PM at that time, Tony Blair. He sets out the vision (Fairclough 2003) of this white paper. He states, that he believes people with ID are so affected by discrimination and prejudice that they effectively withdraw from wider society. (This will be discussed at length in a later chapter analyzing the

discourses of Valuing People.) In order to re-engage, they are to be provided with new opportunities to lead a *'full'*, *'active'*, *'rewarding'* and *'valued'* life, in which they might *'play their full part'*, hence resulting in a *'brighter, more fulfilled life'* (DH, 2001 p1).

It is worth noting he only refers to the difficulties and anxieties parents

'of disabled children' face, in finding *'the right care, health services, education and leisure opportunities for their sons and daughters'* (DH, 2001 p1).

This could equally apply to the parents of adults with PIMD. Unfortunately, it is not until p100 (of a 120 page document) that there is any discussion of *'additional or complex needs'* DH, 2001 p100). The manner in which these needs are itemized, suggests the writers do not have any familiarity with the range of multiple impairments and complex health, social and psychological support needs, an individual with PIMD will have.

Indeed, according to Burton and Kagan (2006)
' those who have such a profound intellectual impairment that their communication is very limited are absent from the picture. The complex health needs of many (mentioned in VP's section on health) and the need for knowledgeable and skilled specialists is not emphasized here. A kind of inadvertent trick takes place, where the least impaired people are used in the imagery to stand for all the others ..' (P 301).

Carnaby (2001) used the Editorial of The Tizard Learning Disability Review, in an attempt to redress the lack of *'knowledge of what is really going on' (p2)*. It is worth noting this was published the same time as Valuing People (DH, 2001). He discusses the relative lack of literature, aimed specifically at community services (practice and provision) for those with PIMD. He maintains this is because *'they are one of the last groups to leave long-stay hospital'* (Carnaby, 2001 p2). However this overlooks the fact that the majority of adults with PIMD live with their families (Emerson, 2004). Carnaby (2001) describes the challenges including;

'the diverse and increasingly complex needs presented by this population' and *'how the needs are perceived by others'* (Carnaby, 2001 p2)

He acknowledges the differing philosophical approaches (medical and social) and argues for WHO style functional assessments, of how PIMD impacts on individual's daily lives. These assessments ought to inform service provision. He further discusses the need for service audits, to review and identify further specific issues. There is a clear outline on definition, as he also agrees clarity is needed. He uses the Lacey (1998) and WHO (1992) definitions.

He goes on to outline the need for '*a respectful developmental approach, which acknowledges the individual's abilities and disabilities*' (Carnaby, 2001 p3).

Notwithstanding the underlying philosophical tensions, he argues for the necessity of medical and social support. Yes, these people will often have a lifelong need for medical interventions, but they '*also need to experience a quality of life built on relationships with others* ' (Carnaby, 2001 p4).

He uses the editorial and papers cited therein, to drive home his argument, which is for recognition of the extent of need experienced by people with PIMD and an understanding that specialist services might not necessarily '*meet the 'criteria' for ordinary living approaches*' (Carnaby, 2001 p4). His concerns are echoed by the initial report from the PMLD Network (2002) published in response to VP. This report highlighted

'*… the way it (VP) does not: use consistent terminology, identify that children and adults with PMLD are amongst the most excluded in our society, identify children and adults with PMLD as a priority group, make any specific objective or sub-objective for people with PMLD, identify family carers of children and adults with PMLD as a priority group*' (p2) and further argues, '*… it could be said that Valuing People accurately reflects the problems facing children and adults with PMLD – we don't know how to describe them and therefore we don't know how to accumulate the information required to gain an accurate picture of their needs*'(PMLD Network,2002 p2).

A few years earlier, Wing (1998) published a paper arguing for an acknowledgement of individual's differences, as opposed to the way she saw the policy of normalisation, being carried out. She argues as a parent and as a psychiatrist, whose research has enriched understanding of autism.

She is concerned that normalisation is often taken to mean that '*disabled people can and should behave as if they have no disabilities and that they should all want to live in the same kind of setting*' (Wing, 1998 p24).

She goes on,

'*the idealists fail to recognize the enormous differences between people in general, let alone those with special problems*' (Wing, 1998 p24).

Carnaby (2001, 2004) and Wing (1998) are two examples of professionals with an insight into the specific and particular needs of this demographic, yet their expertise does not appear to have informed VP.

Burton and Kagan (2006) have attempted to disentangle or decode the mix of ideologies inherent in VP. They point out,

'*…. there has been no critical analysis of VP that sets it in the broader political –economic context of social policy, while simultaneously focusing on the needs of learning - disabled people and their allies.*' (Burton and Kagan, 2006, p299).

This study is attempting to do just this, albeit focusing entirely on individuals with PIMD. The section on discourse analysis will analyse and discuss these notions. For example, the problem of ID is currently framed within the social exclusion discourse. The key to overcoming this problem is seen as accessing the community. This is deeply problematic for those with PIMD. For example a search of the Changing Places (2013) website could find no suitable toilets in the inner London borough and one was identified in a hospital in the outer London borough. These two boroughs were the location of the interviews and focus group discussions that were a feature of this research. Apart from this practicality Berry (2010) notes,
'*what the implementation of such policies often seems to ignore is the **meaningfulness** of community involvement/inclusion*' (p174, author's bold type).

Indeed the Inclusion Europe report (Schadler et al, 2008) was entitled 'The Specific Risks of Discrimination' and concluded that '*the more mainstream oriented services become, the less people with severe disabilities are part of target groups*' (p54). They also pointed out *'there is a high risk that persons with complex disabilities do not profit from these efforts'* (p82) towards greater empowerment through self-advocacy.

Carnaby's (2001) concerns are echoed in the initial report by the PMLD Network (2002), which was published in response to VP. This report highlighted

'… *the way it (VP) does not: use consistent terminology, identify that children and adults with PMLD are amongst the most excluded in our society, identify children and adults with PMLD as a priority group, make any specific objective or sub-objective for people with PMLD, identify family carers of children and adults with PMLD as a priority group'* (p2). The report argues, '… *it could be said that Valuing People accurately reflects the problems facing children and adults with PMLD – we don't know how to describe them and therefore we don't know how to accumulate the information required to gain an accurate picture of their needs'* (PMLD Network, 2002 p2).

Mansell (2008) points out the soft policy has no hard targets. The vision and aspirations of VP are not tied to implementation timetables or resource allocation; rather, they are about

'*enabling people to realize their civil and human rights in all aspects of their lives, therefore as policy it has implications across government'* (Mansell, 2008, p12).

One of the few actual targets of VP was the closure of long stay hospitals. However, the idea of community living for people with the complex support needs inherent in behavioural issues, often described as challenging has not been realized. This, he argues, is to do with the growing market in social welfare, which has seen a growth in high cost low value, residential homes away from local areas. He also cites the lack of advocacy, as another reason the policy is not being realized.

Whitehead et al (2008) published an overview of ID policy in four UK counties. They examined current policy (i.e. Valuing People) and its links to the wider policy agenda. Their paper describes how the proposed key outcome of VP, i.e. social inclusion, addressed the issues of housing, employment, general health and education. Unfortunately, four, five, six and seven years down the line, the gap between rhetoric and reality was still apparent. Of particular concern were the responses to these consultations by family carers, who voiced their concerns about how achievable the goals were, especially for individuals with complex

needs. The paper sets out the new priorities and challenges for the new three-year delivery programme.

Bochel et al (2008) have broached the issue of representation via advocacy. As they point out the government's agenda, which incorporated the notion of modernisation, was inclusion. Making one's voice heard was grounded in the belief that this would produce better politics and therefore better outcomes. The emphasis is on speaking up, but, the authors ask, what about those who literally cannot speak. They do not have an advocate or organizational voice. Representation, therefore, is a major unresolved issue. Who represents those with PIMD? Currently, the preferred source is the organisation PeopleFirst (2011). There is a difficulty with this, as they have a very particular political approach. Their website states very clearly, with regard to self-advocacy;

'everyone can make a choice .... through self-advocacy people's support needs get lower. Once people start to be treated with respect and given responsibilities, they become more independent and find out just how much they can do for themselves.' And, *' we do not think in terms of medical labels like autism .... we look at support needs. Some people need a shoulder to cry on every now and again, some people need help understanding instruction manuals, some people need a push to get out of a chair'* (PeopleFirst, 2011).

And some people, such as those with PIMD require one to one or two to one support with every aspect of their daily lives, 24 hours a day. Some people have very complex medical support needs, or need to be tube fed; some people have multiple epileptic seizures, daily. Some people have no sight, no hearing, and are physically totally dependent. Some people's lives are so sensorily chaotic that their only response is to engage in constant self-injurious behaviour. Yet this remains unacknowledged.

Sherborne (2001) attempts to broach this subject in the context of devising a movement class, by referring to the wide ranging individual needs of those with PIMD. She particularly notes the difficulty for workers, when trying to manage a group of people, which will include those who have profound physical impairments and those who *'have marked emotional and behavioural difficulties. These people may be destructive and aggressive to others in the group'* (Sherborne, 2008, p92).

It appears that there is a negative connotation associated with the concept of high support needs but it is unclear why. The sense is of someone deciding there are good words such as self-advocacy, independent, inclusive and bad words, such as dependent or specialist, which cannot be tolerated.

Drake (1990) describes Stevenson's notion of *'persuasive definition'* (p117). This is the manner in which language, which carries an emotive meaning, may be exploited. As an example he points out that the term institution vs. de-institutionalisation conveys emotionally laden connotations of good versus bad, yet evidence exists to demonstrate merely moving into smaller services, will not necessarily reduce bad examples of care (Sinson, 1990). He also discusses the manner in which the term community fulfils the requirements of vagueness necessary for persuasive definition, in having two meanings: a socio-political-geographical area and a friendship network. He points out that

'*the danger lies in confusing the two meanings in a glow of nostalgia and fantasy so that geographical location is expected to yield friendship networks* (Drake, 1990, p117).

This notion of persuasive definition is alluded to in Burton and Kagan's (2008) criticism of

'*the utopia painted by VP, which sees people making choices about activities in pleasant neighbourhoods, usually suburbs, with plentiful community resources…… they are likely to have friendships and relationships* ' (Burton and Kagan, 2008, p308).

They query the assumption that in order to have value, disadvantaged groups must aspire to *'fulfill society's idealized norms'* (Burton and Kagan, 2008, p306). As Drake earlier pointed out, ' *these assumptions seem to promote an essentially negative conception of differentness* ' (Drake, 1990 p128).

This study will elaborate further on the use of O'Brien's Five Service Accomplishments (1987), which are seen as the UK version of the normalisation approach (Nirje, 1970) which was itself extended by Wolfensberger (1972) into his own theory of idea of Social Role Valorization (SRV). This approach encompasses ideas of social inclusion, which were to be achieved by person centred planning. O'Brien amalgamated ideas of SRV and the SM of disability and these have clearly influenced VP. There is a shift away from acknowledging individual deficits, which makes it very difficult to then argue for specialist services. Indeed, the current postmodern ideas of ID being purely a social construction (Goodley 2001, Williams, 2006) receive short shrift from Byrne in Carlsson (2010); where he opines,

'If we abandon the label and the caring institutions which properly go with it, we will have cut off a significant minority of human beings form aid and help which they need' (p90).

Charles Henley (2001) worked for twenty-five years managing various day centres for adults with learning disabilities. He argues that the need for specialist and structured day services, amongst other things, ought to be acknowledged. He sees services having a vital role to play in the ongoing relocation of people with ID into the community. He believes there is fundamental misunderstanding and misuse of the aims of normalisation, which has huge implications for the future provision of services for people with ID.

He elaborates further in Henley (2005). This book was published as an extension of the original paper (see above). The aim was to provide a comprehensive insight, covering a period of fifty years, into the range of issues that are seen, by Henley, to have dogged the development of a national policy for services for people with ID.

As he sees it, there ought to be a

'single service solution'. ' … a single agency with protected financial support, a national policy, standardized specialist training resources, and a competent inspectorate' (Henley, 2005 p164).

He argues further, that

'the high costs of the proliferation of senior posts created to facilitate the implementation of Valuing People, would make the cost of setting up such an agency seem very small in comparison' (Henley, 2005 p165).

He is very concerned about the lack of shared knowledge between diverse departments. In the same year, for example, that VP was heralded as 'A New Strategy' (DH, 2001 pi), with its inherent visions of *'rights, independence, choice and inclusion'* (DH, 2001, p3), Stalker (cited in Henley 2005) referred to the conclusions of the Social Services Inspectorate Report (SSI, 1998) that

' local authorities in England and Wales had identified 'sound principles' for their services for people with learning disabilities, namely, 'promoting independence, respect and community presence' (p165).

Further the report found that

'most day centres were diversifying to offer people a range of activities that included the encouragement of other sections of the community to use the buildings; attendance at further education colleges, use of mainstream community resources, voluntary work, work experience and paid employment' (p165).

This needs to be looked at in light of the only hard target of VP, which was to relocate people from long stay NHS hospitals. It is worth noting that the almost exact same number, who have been relocated are now living in privately run institutions.

Henley is highly critical of these ideas of relocation, and comparisons must be drawn here to Drakes earlier argument regarding persuasive definition. Henley is also critical of the soft target visions and queries how effective

'the fragmentation of responsibility to different agencies concerned with recreation, education, employment, medical, emotional and psychological needs', can be. In reality he sees this as leading to *'the duplication of bureaucracy and waste of human and financial resources'* (Henley, 2005 p174).

This move to an ad hoc mode of delivery, cannot be successful, since,

'success depends on a comprehensive overview of needs being consistently and competently maintained and monitored and an efficient process of coordination carried out, within a structured and specialist organization' (Henley, 2005, p175). He further argues, *'the nature of day service provision should be influenced by those who will be most affected by changing policies'* (Henley, 2005 p175).

After all, surely those with real experience of the client group, have a better understanding of their specific needs? A part of this understanding is to acknowledge *'that irreversible brain damage does exist'* (Henley, 2005 p176). This is another counter to the aforementioned SM approach, which denies biological assumptions and promotes the social construction of ID.

2.5 Rights

Baylies (2002) recognizes the prominence of the rights based approach, but she aligns this with a human development approach. This emphasizes the notion of capabilities and uses this idea to examine the implications for disability. She argues, that this approach might,

'become a powerful means for identifying the responsibilities of governments and external agencies in genuinely equalizing opportunities' (Baylies, 2002 p725).

Nussbaum (2006) has thoughtfully broached the subject in her recent treatise on social justice. She cites the example of a young woman called Sesha, who despite her profound impairments has '*a dignified and fruitful human life*' (Nussbaum, 2006 p194). However, Nussbaum is keen to point out this is due to the work of her parents and her caregivers. She refers to Kittay (1999) who is Sesha's mother and who has written extensively herself on the subjects of caring and dependency.

Swain (2004) notes that the human rights approach is a minority worldview, represented as individualistic rather than collective. He quotes Legesse (1980, cited in Swain)

'If Africans were the sole authors of the Universal Declaration of Human Rights, they might have ranked the rights of communities above those of individuals' (Swain, 2004 p57).

Swain also cites Turner's (1993) concern that concepts like citizenship can actually repress important detail. He describes the manner in which

' *… various types of particularity must be subordinated* ' (Swain, 2004 p57).

Turner is referring to the situation for aboriginal groups who may assimilate at the expense of losing their own culture. However, this idea could equally apply to the issue of PIMD. Ideas of independent living, full community participation and employment for all disabled people, deny the particularity of this demographic, to the extent where they are actually reconstructed as people having aspirations or able to live independently.

2.6 Independence

Goble (cited in Swain, et al, 2004) in a discussion of intellectual impairment and independence, acknowledges,

' *At the same time intellectual impairment, when severe, profound and/or degenerative, does impact on individuals in ways which challenge the current thinking of us all about issues of dependence and independence. Even the disabled people's movement, not a place that people with intellectual impairments have always found very welcoming (Stevens, 2004), needs to*

seek ways to pursue rights, citizenship and enablement which are not necessarily built around the concept of personal independence. There is a need to develop and incorporate models which support those disabled people who are, because of the nature of their impairment as much as society's response to it, always going to be dependent on others for control and choice making, as well as physical aspects of day-to –day life' (p45).

In other words, he acknowledges this population as having needs, which are different to the needs of individuals with ID who can self-advocate, in the literal sense of speaking up for themselves. He defines the challenge to society as one, which needs to demonstrate value and respect for individuals with PIMD. His answer is advocacy as a right, not an option.

When writers discuss independence in the context of adults with PIMD, it is often with regard to the idea independent living. Ward and Cooper (2011) claim

'Living independently does not mean living alone without support – it is having a place to live that meets the person's needs, with an appropriate level of support, to ensure that the person has choice and control and his or her rights are met' (Ward and Cooper, 2011 pp 40-41).

Smith (in Kristiansen, 2010) queries the

'*ideal of independent living often promoted within the DRM as a goal for disabled people intended to reflect characteristics of normal or ordinary citizenship'* (Smith, 2010 p19).

Miller (1998) describes a woman who was overloaded with support and equipment designed to make her independent, to the point where she spent her entire day indoors attempting to maximize her daily living skills but to the detriment of any social or leisure activities. Miller (1998) makes the point that whilst it is important to attempt to enable an individual

't*o have as much control as possible over their personal activities of daily living, it is also about developing a means to ascertain whether or not that individual wants to spend time and effort in developing independent skills'* (Miller, et al, 2006 p41).

2.7 Choice

Finlay et al (2008) conducted a nine month ethnographic study which sought to explore the mismatch between policy goals of service user empowerment, via increased choice and control and support worker practice in three residential settings for adults with ID. The results

demonstrated a range of obstacles, such as service values and agendas, inspection routines and a focus on attending to bigger decisions in people's lives. The paper outlines ways to achieve choice and control via their promotion at the everyday level. It is frank in recognizing this is not so easy to enact. The strategies require, '*a degree of specialist knowledge or a culture of consistency, debate and evaluation, which may be lacking from services '(Finlay, et al, 2008 p359).*

The report did not hold back from recognizing and discussing this ongoing difficulty. They ascribed it to a mixture of staff perception (usually misguided or completely wrong) of the policies themselves and the capacity for their residents to understand. As an example, the researcher noted on a number of occasions, staff insisting on using overly complex verbal interactional attempts, including constant questions, to residents who rarely communicated verbally and gave no indication they could understand or respond. This is a good example of the confusion around the concept of choice. Brown et al (2002) state that in order for an individual with ID to make daily choices,

'*There has to be a genuine choice available. They need an understanding of the concept of choice. They need to be made aware what the options are in a way they understand. They need to have experienced the options previously. They need time and a means to communicate their choice. They need to be able to experience the consequences of their choice. Staff need to act on the choice communicated.' Further, people need to be aware of the different types of choice, 'Accept / Reject. Like / Dislike. More / Enough. X or Y. X, Y or Z. Yes / No. Open Question and Initiates choice making*' (Brown, et al, 2002 pp 9-10).

All of this refers to simple daily choices. There is no further elaboration of different levels of choice. It could be argued that an individual with PIMD may be supported to make a basic choice, in that they could accept or reject an initiation. However, when referring to choices about where to live or who to vote for, it is deeply disingenuous to maintain that this level of choice making is possible.

Clarke et al (2006) elaborate on this, by discussing specificity of choice as a particular policy mechanism exploring choice of school or college. Choice might also take the form of practice, involving exchange, as in exchange of resources (cash) for object, service or outcome. And choice can also be described as having generic, social and political value. Indeed, they argue, oscillation between these meanings has proved to be a powerful discursive resource. Whilst not having an answer, they do at least raise a query about

individual's intellectual capacity (or not) to exercise choice. And they question why this difficulty is not acknowledged in the choice agenda.

2.8 Inclusion

Redley (2009) explores the welfare rights of adults with ID in terms of New Labour's Welfare To Work policy. In particular it discusses the UK's mixed welfare economy and its impact on services including residential care services for adults with ID. Of major concern is the consolidation of services into the hands of a few, very large provider organizations (Redley refers here to Banks 2006, Drakeford 2007, Hencke 2009, Scourfield 2007).

Redley's critical analysis demonstrates that

'*residents have little or no control over the services they receive'* (Redley, 2009, p499*).

He argues this is because the organizations,

'*are accountable to their shareholders, the local authorities, independent regulators, but not to individual residents* ' (Redley, 2009, p499).

This becomes even more problematic, in the common example where one company owns the home and another company manages the service provided there. The real concern, being raised here, is the economic pressure to be efficient. Redley (2007) gives a very clear account of what this means in the real world. He argues, that basic care, washing and dressing individuals, becomes the battle ground for these efficiency gains. In the end there is a limit to how many people a worker can wash and dress in x amount of time. He concludes that the loser is always the service user, as the company will achieve their efficiency gains by eventually substituting skilled and therefore more expensive support workers, with cheap, less or unskilled agency workers.

In this climate, it is clear that an individual needing more support, more understanding of the complex nature of their support needs and more time to carry out the support, is going to lose out. When that individual has PIMD, i.e. is not able to self advocate, has no family member or independent, objective other, monitoring their care and support, it is unclear who monitors this.

Philo and Metzel (2005) argue that by remaining '*outside the participatory mainstream*' (p82) people with ID might just as well still be living in the asylums of yore. However, they temper this, by acknowledging such simplistic assumptions around notions of inclusion and exclusion are oftentimes confounded by sensitive fieldwork, i.e. interviewing people with ID. Some people express a preference for supposed places of oppression; that is, the care home or the day centre. They report feelings of being '*wanted, valued and befriended*', whilst it is in the '*ostensibly inclusionary spaces of independent living and paid employment, that the worst senses of exclusion, of being unwanted, unvalued and friendless arise*' (Philo and Metzel, 2005 p83).

This is where the views of family carers, will contribute to this study. With modernization and the move to accessing the community, it is unclear how many day centres consulted with their attendees or their families over the new service structure. Since the introduction of self-directed support (SDS), Local Authorities (LA) are insisting all people with ID, can find their own activities in their local community. With the budget cuts introduced since the new coalition government, this will only increase. Berry (in Firth et al, 2010, p174) queries the meaningfulness of community involvement/inclusion for individuals with PIMD. She is concerned about new policy led approaches, which fit with ideas of inclusion but are of no benefit to the person themselves.

Forsyth et al (2007) define the concept of participation as the involvement of the individual in life situations and according to the authors it replaces the concept of handicap. Accordingly participation is recognised to be determined by both intrinsic impairment and environmental or contextual factors. The latter includes not just attributes of the physical environment, but also societal values and structures as reflected both at the macro level of public legislation and policy and the micro level of attitudes as experienced by friends, family and the public.

2.9 Post structural approaches

Goodley (2001) sets out to challenge existing epistemologies, (i.e. the tragedy model of disability) and to develop a '*socio-political, historical and culturally sensitive epistemology*' (Goodley, 2001 p225). Goodley argues that the starting point for any subsequent theorizing

of impairment with regard to ID is problematic if directed by biological assumptions. A major difficulty with this stance is that, even though early on he acknowledges that individuals with SID /PIMD are unaccounted for by social theory, he then embarks on a proposed social theory which would only include self-advocating individuals.

Dowse (2001) examines the relationship between self-advocacy and the disability movement in Britain in the light of social movement theory. Using the concept of collective identity as it is explored in social movement theory, the analysis examines why the disability movement's promotion of a strong disabled identity may be difficult to achieve for all its constituents, particularly people with ID. Additionally the concept of symbolic production within social movement theory is used to explore how the movement uses the social model of disability as its collective action frame.

Realignment of this frame, she argues, is taking place within the movement and is reflected in debates within disability studies about the role of impairment. The voices of people with ID remain silent in this debate. The paper concludes by arguing for the recognition of social, psychological and cognitive difference as pre-requisite to an inclusive theory and politics of disability. It could be argued, that by incorporating ideas of agency via self-advocacy, policy makers are being supplied with '*frames that supply them with underlying structures of beliefs, perception and appreciation*' (Fischer, 2003 p144). Hence the problem of PIMD is reframed as lack of self-advocacy, which fails to acknowledge the underlying reality. In other words, denying the biological brute facts. For example, ' *…. the presence of an extra chromosome 21 is a brute fac*t ' (Kristiansen, et al, 2010, pp 47-49).

By the use of assumptions such as everyone can self-advocate there is a corresponding lack of acknowledging differences. Shakespeare (2006) asserts that these differences are just as important as the similarities. Wing (1998) expressed a concern that ideology is denying the reality of difference. Concannon (2005) recommends including an awareness of differences in practice and policy development. Gooding (cited in Shakespeare 2006) calls on us to recognise these differences.

'*The strategy of promoting employment, while very desirable, will also leave a residuum of unemployed and unemployable disabled people. Disability includes intrinsic limitation and disadvantage*' (p66).

Jeffreys (cited in Thomas, 2007) calls for a critical reassessment of prevailing constructionist notions that appear hostile to biological recognition of difference. He argues we need to

'learn how to accommodate rather than demonize the study of the biological aspects of our bodies' (p128).

2.10 Summary of concerns

Leyin (2010) has called for clarity of definition of the terms used to describe ID in line with the international community and Davidson (2010) warns against adopting purely social/adaptive measures. The confusion with terminology is compounded by those researchers (e.g. Goodley 2001, Williams 2006, Grieg, in Holman 2001, Armstrong 2002, Coles, 2001) who believe the best way to represent ID is via a social model. This becomes problematic when it is apparent they have only included accounts of people with milder ID in their research.

Those who do explore issues associated with supporting people with PIMD (e.g. Lacey and Ouvrey, 1998, Carnaby and Pawlyn, 2009) or issues around advocacy such as Bochel (2008) or specialist services such as Byrne (2010), Henley (2001, 2005), Mansell (2008, 2010), and Davidson (2010) all argue for an understanding of the complexities surrounding issues of support for those with PIMD. Simplistic notions of inclusion, they argue, are not necessarily the best way of accommodating these issues (Firth, et al 2010). Drake (1990) and Burton and Kagan (2006) have also expressed concerns about the use of language, which tends to dichotomise.

Parrot (2008) and Emerson (2009) have published data specifically demonstrating the rise in number of people with PIMD and predicted future numbers. This led to Royal Mencap (Williams 2008) pointing out the glaring lack of social care funding. As Cramp (2003) estimated the new money linked to VP amounted to something like £12 per head for all those with ID. Williams estimated the figure needed to bring about real change in the lives of those with PIMD, was more likely £300 million per annum. Mansell (2006, 2010) has shown it is still the families who fill this gap by providing the care themselves.

This groundswell of opinion was highlighted by Dawkins (2009), whose report notes that the needs of people with PIMD were either overlooked or not being met. The cornerstones of the

VP policy, presented as rights, independence, choice and inclusion are shown to be especially problematic when used in the context of services for people with PIMD. This could be ascribed to the lack of fit of the social model and normalization approaches, with the brute fact of profound intellectual and multiple disabilities. In order to ascertain what led to this lack of fit it is the contention of this thesis that the answer lies, not so much in the delivery or lack of services, but in the manner in which this group of people was represented or not, in the policy from the outset. It further contends that this lack or misrepresentation aids and abets poor provision and delivery of appropriate specialist services.

The next chapter will outline the manner in which this thesis will robustly explore the lack of fit from a number of angles, i.e. policy analysis, families' experience and formal care workers understanding of the new policy.

Chapter 3 Methodology

3.0 Introduction

According to the Overview report of the Valuing People Research Initiative (Grant and Ramcharan, 2007), Valuing People (DH, 2001) *'embraced the social model of disability'* (DH, 2001 p77). Therefore it was deemed necessary to fully appraise this particular model and to explore the manner in which the notion of ID (and particularly PIMD) was accounted for. This then informed the analysis of VP in order to answer the first research question

'To what extent is the Valuing People (VP) policy informed by the social model approach to disability?'

Once this appraisal was completed, it seemed apt to find a way to compare and contrast those findings with the 'on the ground', understandings of family and formal support workers and highlight the areas which were not reconciled. This led to research questions numbers two and three.

'How do family carers of individuals with PIMD make sense of the philosophical underpinnings of current policy?'

'How knowledgeable are formal care workers of the VP approach? Is there any evidence of a theory-practice gap?

3.1 Research Problem

The research problem under exploration in this study is defined as the lack of fit, between the current philosophical frameworks underpinning government policy and the broad ranging and complex needs of individuals with PIMD. It contends that the lack of representation as a distinct group, known as people with PIMD, has a negative impact on service delivery and the lived experience of this population. The research design selected to clarify this problem, needed to incorporate a critical exposition of policy with as close to first hand accounts of the lived experience of the target population as possible.

3.2 Objective

The overall objective was to investigate the research problem and identify the factors, which might have contributed to the perceived lack of fit. Specific critical discourse analysis of the VP policy including its drivers of rights, independence, choice and inclusion was considered necessary in order to evaluate the impact of these on the lives of individuals with PIMD. This impact would be further examined by exploring family carers' and care workers' responses to questions derived from the aforementioned analysis of the policy. Additionally this thesis was seeking to develop a research method, which might enable individuals with PIMD to be more meaningfully involved in wider consultations and in their own ongoing action research. Ultimately the purpose of this thesis was to further raise awareness of this particular population and to contribute to the published literature, some understanding of the impact of government policy on their lived experience and that of their carers.

3.3 Research design

The qualitative design of the research reflected the intention to investigate the research problem with data collected from a number of sources, in order to provide a more descriptive explanation. This triangulated approach was considered the most appropriate route to answering the research questions and to highlighting the research problem. The thesis therefore incorporated a critical discourse analysis (CDA) of government policy documents, with data obtained from interviews and focus group discussions with formal and informal carers.

The interview /focus group schedule of questions were derived from an examination of the VP objectives. The responses of these lay people, who have day- to- day experience of the target population, were compared and contrasted with the formal policy discourse. Additionally, the focus group discussions (FGD) were preceded by a short film of an individual with PIMD, in various situations, designed to prompt discussion of the key cornerstones of the policy, namely rights, independence, choice and inclusion. These concepts have become common parlance within service settings and research, yet it has not been established what they actually mean for individuals with PIMD (Lawton 2009). Therefore, the film was shown with no prior information, in order to explore emergent definitions of these topics.

We all have human rights, according to Article 2 of the Universal Declaration of Human Rights (United Nations, 2011). However exercising one's rights as an individual with PIMD, is at the very least, extremely problematic and almost certainly depends on the services of an advocate and or family carer. Independence as a concept sounds like a tautology for someone who requires care and support twenty-four hours a day. Choice might notionally exist on many levels. For example, it could be exercised via a very basic acceptance or rejection of food. It could be seen as an either / or context specific notion. Equally it might be represented as a choice between one or two concrete objects, or by choosing between multiples. Abstract choice making such as voting, occurs at the higher end of the spectrum (Kelly 2000). If an individual can only be presumed to be making a choice by not spitting out food, it is not cognitively possible for them to make next level choices. It is disingenuous of service providers to state these individuals have been consulted about their choice of health, housing, social care or support service. Inclusion is another very broad notion, which encompasses abstract ideas to do with equality of access and opportunities. All of these concepts have been drawn together under the umbrella term personalisation and the Department of Health have published good practice guidance for local implementation (DH, 2010).

With all of this in mind, the researcher required filmed excerpts of an individual engaged in activities, which could be construed as making a choice, exercising her rights, demonstrating independence and accessing the community. The point of showing the film, with no explanation, was to see if the care workers also interpreted the activities thus. If not, then the question arose as to what they understood the key cornerstones to mean and what relevance they believed they had for people with PIMD. And further, to explore whether or not those heuristic understandings differed from the formal policy discourse as represented within VP (DH, 2001,2009).

3.4 Methodological approach

Taking into account the necessity for depth and breadth of exploration, in order to compare and contrast the formal discourse with lay understandings, the study necessarily had to employ a qualitative paradigm. Cresswell (1994) defines qualitative research as an

'inquiry process of understanding based on distinct methodological traditions that explore a social or human problem' (p162).

An exploratory and descriptive focus to the research is consistent with an emergent design, which incorporates an inductive, analytic style, rather than a hypothesis or theory, which must be proven. The subject under discussion here is very difficult to define and describe, therefore an inductive mode of enquiry would encompass this complexity. Qualitative methods are concerned with discursive descriptions and explorations of construed meanings (Blaikie, 2001). Considering the research questions here are concerned with the sense formal and informal carers make of the new VP approach, a strategy was required, which essentially explored individuals' accounts and interpretations of said policy and how it is implemented.

Bigby et al (2012) refer to the latter stage of their large-scale outcomes survey. Their approach was influential in the design of this study. Face to face interviews and a questionnaire were included in the research design in order to examine staff perceptions and their understanding of the meaning of certain outcomes such as participation and inclusion for people with intellectual disabilities in a long-term study in Australia. They used a combination of interviews and questionnaires in their outcomes survey in order to tease out individual's perceptions and understandings. For this thesis the accounts obtained from formal and informal carers were then set against an examination of the key policy papers.

In another study which aimed to explore the lived experiences of people with ID who had cancer, Tuffrey-Wijne et al (2010) used the ethnographic approach of participant observation combined with interviews with family members and healthcare staff as well as grey data obtained from case notes and reviews. This approach has been also been used by Hubert and Hollins (2006) in their research with people with ID. These studies mainly depended on participant observation and follow up interviews with family members or care staff. Whilst many studies include people with a range of ID, Hubert and Hollins (2006) were clear they wanted to specifically focus on people deemed to lack capacity under the terms of the Mental Capacity Act (MCA). This thesis was likewise concerned to focus on the lives of individuals deemed to lack capacity.

The research design, whilst still qualitative was not however ethnographic. The decision was taken to use data triangulation whereby different groups explore the same topic (Denzin, 1978, Seale 1999). Specifically the triangulated data sources were the lay sphere (family carers), the work sphere (paid care workers) and the policy or formal theoretical sphere (published policy papers). The strength of this approach lies in the method of combining

information from the different sources, which may overcome respondent / insider bias (Yin, 2003).

A comparative element was a feature of the interviews and focus groups. They were conducted in two distinct London boroughs, (one inner city, one outer borough) in order to provide further breadth to the study. It was considered there would be a number of additional features worth comparing, such as access/availability of specialist services, local profile of 'PIMD', via Carers Forums and Learning Disability Partnership Boards, breakdown of numbers living with family, in borough residential care or outer borough residential care and availability of advocacy services (see Appendix C: London Boroughs Comparative Features, p251).

Denzin and Lincoln (1994) emphasise the manner in which qualitative social research seeks answers to questions that stress how social experience is created and given meaning, via accounts of lived experience. Hubert and Hollins (2006) and Tuffrey-Wijne et al (2010) used ethnographic observation with family carer interviews to obtain an insight into these particular individuals' lived experience. The crux of this thesis lies in its fundamental acknowledgement that first hand accounts are not possible to obtain, due to lack of mental capacity in the target population. However, by seeking the views and participation of family carers, who will have a long term keen knowledge of one particular individual and care workers who have a breadth of experience of a wide range of individuals, it is possible to make some informed assumptions about the needs of this population.

Mannan et al (2011) used an interpretivist approach to their qualitative research study, which investigated the complexities associated with the provision of respite services, from a family carers' perspective. Mason (2002) elaborates on the interpretivist epistemological approach as one primarily concerned with data derived from the

' *…interpretations, perceptions, meanings and understandings' (Mason, 2002 p56)*

people have of the subject under discussion. She describes the possible use of data derived from texts, but points out this would be in order to understand how the text was *'constituted in people's own or collective meanings'* (Mason, 2002 p56). Mason's account has direct implications for this thesis, which explores the manner in which individuals interpret the impact of government policy on the lived experience of those they support. In particular this

thesis was concerned to understand what the key cornerstones of the VP policy actually meant for people with PIMD.

The use of an interpretivist approach aimed to produce a deeper, fuller account of this impact, as it required a discussion about how to interpret or understand the participants' various responses. It also afforded the opportunity to position these responses in some wider context; for example, viewed through the individual's own ontological approach. In this way, whilst the study cannot claim to be representative of the entire population of carers of people with PIMD, it sought to include and respect the range of views proffered. Further, by acknowledging the subjective and constructed nature of these meanings, the researcher was also acknowledging her research bias as an interested insider with her own interpretivist epistemological stance.

Ultimately the approach comprised critical realist ontology, with an interpretivist epistemology. When referring to a critical realist ontolology, the realist aspect is the brute fact of PIMD. King and Horrocks (2010), discuss the manner in which the concept of realism is often used to denote ontology as a specific way of understanding our existence in the world. Vehmas and Makela (in Kristiansen et al, 2010) discuss the way Searle (1995) describes the difference between brute physics and biology, i.e. things, which exist, and mental facts such as feelings or perceptions (Kristiansen, 2010 pp 46-47). In other words genetic disorders can be described as ontologically objective, since they have an objective organic basis, which is not dependent on representation. Thomas (2007) notes Bhaskar's term epistemic fallacy might apply when knowledge of things is conflated with the actual existence of things (Thomas, 2007 p34). This is the lack of philosophical fit referred to. On the one hand this thesis attempts to deal with a tangible and real something, i.e. PIMD. However, it is the manner in which this complicated amalgam of definitions has come to be represented that is problematic.

'Discourse constructs the topic. It defines and produces objects of our knowledge. It governs the way a topic can be meaningfully talked about and reasoned about. It also influences how ideas are put into practice and used to regulate the conduct of other' (Hall, 2001: p72).

Therefore, the manner in which language is used (e.g. everyone can self advocate, everyone should work, everyone can make choices) actively constructs a range of expectations and a particular version of reality. This can be unhelpful when dealing with a population whose reality as such needs much clarification.

The critical aspect of this methodological approach refers to a desire to change unsatisfactory or oppressive realities. These could here be described as the lack of a clear definition of PIMD and general misunderstanding and misrepresentation in the literature of the target population. In order to understand the complexities associated with the difficulties of definition, it was necessary to spend time unpicking the various definitions in use. This included the formal discourses inherent in the VP strategy. A critical realist stance was employed in order to consider what the relevance or meaning of these might be. This also required an interpretive and a flexible approach, which allowed for emergent ideas to be produced.

This thesis therefore, acknowledges the reality or the brute fact of PIMD, but also recognizes the role of reflexivity, which in turn theorizes knowledge as a social process (Benton and Craib 2001, Guba and Lincoln, 1994). The manner in which individuals (family and formal care workers) and policymakers attribute meaning to another person's experience was considered, as it is not possible to obtain these views firsthand. Indeed this is the crux of the thesis that people with PIMD have to rely on those who know them well to ascribe meaning to their own unique and idiosyncratic methods of communicating.

By finding a practical way to include an individual with PIMD in the research process, albeit without her discernible knowledge or awareness, it was considered the research design could be described as inclusive. Further justification informed by Walmsley and Johnson (2003) and Walmsley (2013) includes some of the following aspects. Firstly, people with PIMD are rarely included in research and recent attempts have met with varying degrees of success (see C1.8 p29). The researcher was adamant that her decision to embark on the thesis was prompted by concerns with the lack of representation of people with PIMD in the original Valuing People (DH, 2001, 2005) strategy and subsequent government policy (DWP et al, 2005). To this end the thesis seeks to further the interests of people with PIMD by exploring their lack of representation in depth from three different sources, policy, interviews and focus group discussions.

The use of filmed excerpts of the woman in her daily life, informed the focus group discussions, rather than her simply being an object of study. The film is the researcher's attempt to place an individual with PIMD at the heart of the research process. By including filmed excerpts of an individual engaged in daily aspects of her life, the researcher wanted to demonstrate a meaningful way that people could be involved in consultation and in their own action research. Development of this approach would therefore be a method for transferring learning from research to practice, which in turn could lead to better services and ultimately better lives for people with PIMD.

Eva Kittay (in Kittay and Feder, 2002) describes the difficulties encountered in attempting to be the voice for her profoundly disabled daughter. She describes the manner in which she *'considered how I interject my daughter into this critical discourse '*(Kittay, 2002 p259). She points out that the very fact she has to speak '*not only about her but for her'* (Kittay, 2002 p259) to an audience, whilst apparently a negative account of what her daughter cannot do (i.e. speak for herself) is in reality a '*synecdoche for all that she is unable to do'* (Kittay, 2002 p259). The use of filmed excerpts in this thesis and by extension for future consultations, could be considered to provide a more impartial glimpse into an individual's life than a verbal account might do.

Reflexivity was a constant feature of the research. The researcher was very clear about her position, which could also be described as triangulated. As a parent, professional and academic, she has long-term experience of the target population and those who support them through her own personal experience, therapeutic work with families and training of care workers. As the parent of an adult with PIMD she had a degree of insider status with the family carers but this could also have positioned her as an outsider with the care workers. Servian (1996) has explored the '*contradictions and tensions in power relations between carers, users, workers and managers'* (Servian, 1996, p1). His qualitative study, which employed interviews with various individuals involved in learning disability services, found little evidence for a shared view of empowerment.

Here though, it could be said the researcher was straddling '*the space between'* (Corbin Dwyer, 2009 p60), neither completely the same as, or completely different to, the participants. Arguably this position helped to minimize researcher bias.

Brewer and Hunter (1989), Lincoln (1995) and Creswell (2003) all refer to the use of triangulation as a well recognized research method, which can increase the credibility and dependability of findings. They describe the use of overlapping methods for delivering rich descriptions, which allow the reader to have a clearer understanding of issues under discussion. Miles and Huberman (1994) maintain the more the researcher is open about their own beliefs and assumptions, which drive the research and inform the methods selected, the higher confirmability the findings will hold.

After discussion with the research supervisors it was decided not to conduct a formal pilot study. Firstly, there was no need to fine tune the interview/focus group questions (see Appendix B p259), as they were already devised from objectives set out in the original Valuing People (DH, 20001) document. And secondly, a pilot would have necessarily involved the same participants (or at least some of them) and the concern was if they were a part of a pilot study, they could not be included in the main research. This was primarily with regard to the focus group participants, for whom the film had an element of surprise and novelty which would be lost if they had already participated in a pilot. (For further reflection on this, see pp99-100).

To summarise, the explicit strategies employed to reduce bias and increase internal validity included the adoption of well-established research methods for collecting and analyzing the data. These methods were critical discourse analysis, semi-structured interviews and focus group discussions. The use of this triangulated approach was considered to lend credibility to the research process as the use of focus groups and interviews provided a range of informants, in addition to the documentary data (Denzin, 1978, Seale, 1999, Yin, 2003).

All participants were provided with an Information Sheet, which outlined this and further explained the reason they had been selected to take part. Additionally all participants were offered the opportunity to withdraw at any time, which meant only those who were willing to participate, did so.

Iterative questioning was employed, especially during the focus group discussions, to ensure clarity. For example, the workers at one particular site would answer a question by referring to individuals who did not have PIMD. The researcher had to ensure they were focused on the target population by using probing style questions to avoid any ambiguity in the answers.

The researcher acknowledged her research bias as an interested insider (p71, 73, 89 and 128) however her insider /outsider status i.e. straddling '*the space between*' (Corbin Dwyer, 2009) was considered to add credibility and rigour to the research. She also kept a research journal with reflective notes (see p200) and had regular meetings with her Supervisors to discuss the work in progress. She made reference to her academic experience (p12) in the area and incorporated detailed description via depth and breadth of discussion of the subject under scrutiny, i.e. PIMD and Valuing People policy (see Chapters1 and 2).

Whilst the findings from this small-scale investigation may not necessarily been generalized to the wider population, it is envisaged the same investigation could be conducted in other settings. For example the interviews could be conducted in a formal carers centre instead of individual's homes and the focus group discussions could be held in a residential group home instead of a day centre. Equally, another individual with PIMD could be filmed, engaged in similar or differing pursuits by their own support worker. The same interview/focus group general questions could be derived from an analysis of the objectives and targets outlined in the original VP (DH, 2001) document. These reasons enhance the external validity of the research.

3.5 Research Methods

As stated the methods adopted for this study were a critical discourse analysis (CDA) of government policy documents, semi- structured interviews and focus group discussions, prompted by viewing a ten-minute film of a woman with PIMD. Knight et al (2006) discuss the benefit of a triangulated approach in their report into ways of consulting with children and young people with learning disabilities. They specifically referred to Preece (2002) which employed semi structured interviews with workers and parents, documentary evidence and '*being there*' observation (Knight et al, 2006 p16) to explore childrens' experience of short-term residential care. Yin (2003) considers the strength of a triangulated approach lies in the method of combining information from the different sources. For this thesis these sources could be described as the lay sphere (family carers), the professional or chalk face sphere (care workers) and the policy or formal theoretical sphere (the VP policy).

It was considered this approach would yield a broader range of information, which could then be compared and contrasted. For example responses from care workers could be compared to the same responses from family carers to ascertain any areas of (in) congruence with the policy objectives. Likewise care workers emergent discussions prompted by viewing the

filmed excerpts, could be contrasted with family carers lay understanding of the same VP concepts.

CDA was selected, as this method enables exploration of texts, which might further demonstrate the relationship between discourse and society, text and context and language and power (Fairclough 2001b). Chouliaraki and Fairclough (1999) discuss the ongoing relationship between economic, political and cultural social practices and argue that, transformations, which may take place theoretically, might oftentimes be better perceived, as transformations in language and discourse. In other words, by changing the language are we really changing the social practices? This was the starting point for examining the current trend for experiential or good news stories, fictional narratives masquerading as first person reports and scenarios written as if they had happened, as research data and to illustrate government policy documents in the learning disabilities arena. The strength in using government documents as evidence, lay in the ability to analyse from source. This made it possible to include exact details and provide a broad substantive cover of the issues as envisaged by the policymakers. The documentary evidence, which was subjected to the CDA, provided a factual overview of the key issues regarding adults with PIMD.

The use of interviews as a method of data collection is ubiquitous within the field of qualitative research (Gubrium and Holstein 2002). They are described as, incorporating a flexible open-ended style, with a focus on people's actual experiences. Not simply their opinions, but how they experience their world. This idea of trying to understand something, from the point of view of the lived experience, harks back to Dilthey (1833-1911) and Weber (1864-1920) and the notion of verstehen.

Dilthey (cited in Gubrium and Holstein, 2002, p18) believed this was the goal of social science research. Weber (cited in Gubrium and Holstein, 2002) further emphasized the role of meaning and understanding, referred to as verstehen.

'Proponents share the goal of understanding the complex world of lived experience from the point of view of those who live it. The goal is variously spoken of as an abiding concern for the life world, for the emic point of view, for understanding meaning, for grasping the actor's definition of a situation, for Verstehen' (p18).

The interview schedule of questions was designed to draw out participants' interpretation or understanding of VP policy. The questions were therefore devised to enable discussion, rather than a yes/no answer. This gave the family carers the opportunity to think aloud as it were; to actively reflect on issues deeper than the surface concerns of their support role. Equally it was considered the care workers might be a little cagey about answering if they felt their working practices were being called into question, or that they were under some kind of scrutiny. One way this researcher attempted to gain the trust of care workers was by positioning queries within questions about VP objectives. This also gave staff the opportunity to recount and reflect on where and how practice had improved or not. The responses from those workers who had been in post for a long period of time and could therefore make comparisons were especially helpful.

Finlay et al (2008) have discussed their research investigating staff perceptions of policies, which aimed to increase service user empowerment. Antaki et al (2006) used an ethnographic approach to film actual interactions between staff and individuals with ID in situ. They sought to identify features, which encouraged empowerment and those, which might obstruct. Their research attempted to disentangle the dilemmas for staff in implementing policies, which might conflict with resident's wishes. The researchers had to negotiate access with staff who were not always compliant with these requests.

The use of film here was a device to initially focus the discussion. It was also a form of ice-breaker in the sense that it created a space, where care workers did not need to feel their own working practices were under immediate scrutiny. This was a deciding factor in the researcher's decision to use film of her daughter rather than another individual. All of the families initially selected had sons or daughters attending the day centres in inner London, whilst the researcher's daughter does not. There was a concern that the findings could be affected by using film of an individual who some staff may know but others not. For example workers who knew the individual may have had a keener insight into their behaviours and interactions. There was also a desire to use film of someone with the behavioural support needs described as challenging in order to demonstrate how they can be included in consultations. These people are rarely if ever able to attend the conferences and events that are organised to seek out their perspective.

And as Concannon (2005) has noted there is,

'the need to change the approach to practice and policy development. It suggests that the agenda is not whether people share the same view but that their **differences** *are acknowledged and included in the process'* (p171).

The filmed excerpts utilize the techniques of photo elicitation, whereby the images shown are used to stimulate dialogue (e.g. Harper, 1988, Pink, 2002, Rose, 2007). Photo elicitation, or in this case film elicitation, involves the initial gathering and grouping together of a number of images, which will hold significance for the interviewees. These are shown to the group with the aim of *'…. exploring participants' values, beliefs, attitudes and meanings…'* (Prosser, 1998:124). Further, it provided a platform for staff to demonstrate their observational and analytic skills. In a sense the subject of the film became a palette for their projections and reflections. The film itself is not being analysed here, it is the manner in which the participants respond to it. In particular, the meanings they attribute to the actions of the individual. It was anticipated the viewing of the film could generate responses and insights that interviews would not.

Pink (in Seale et al 2004) discusses the use of video as a prompt or topic for discussion in focus groups and describes the manner in which the elicitation creates a space for personal interpretations. Lapenta in (Margolis and Pauwels, 2011) notes it can also be seen as collaboration between the researcher and participants as the meaning of images is explored in conversation. Harper, (2002) describes the use of an image introduced into an interview setting as one, which elicits a deeper response and different information. This is because older parts of the brain are engaged to process visual images and entirely different parts to process visual rather than textual information.

A viewing of the film, which comprised short snapshots, filmed in real time, but on a number of different occasions, prefaced all the focus group discussions. This was necessary as the ethical aim was to illustrate the individual's lived experience, but not to include any moments of extreme distress or to in any way compromise her dignity. In the discussion, it was acknowledged however, that these less distressed moments are combined with periods of very real distress, which are demonstrated by the behaviours described as 'challenging'. These include head butting her carers, lashing out violently and self-injuring. Whilst these

moments would not be filmed, equally it would not have been a truthful representation of her lived experience, to only discuss her moments of positive engagement.

The actual filming was done by one of the individual's regular support workers and took place within her daily routine. The only proviso was to try and capture moments, which might illustrate the key concepts of rights, independence, choice and inclusion. Using non-professionally filmed excerpts demonstrated the worth of the film lay in what was captured by the worker. The researcher wanted to show that anyone who knew an individual well and had some insight into their behaviours could replicate the produced excerpts. It was considered this also demonstrated the use of filmed excerpts could be incorporated into staff developments and wider consultation exercises.

Nind (2008) discusses the methodological challenges in conducting qualitative research with '*people for whom traditional methods of qualitative research might present challenges for researchers* (Nind, 2008 p3). She refers to Kellet and Nind (2001) which involved people with profound impairments and describes how they involved a network of people known to the individuals, who '*cared about them, knew when they were unhappy, distressed or uncomfortable* ' (Kellet and Nind, 2001 p53).

As noted earlier, the use of video diaries of people with PIMD convey their lived experience more succinctly than the written word. However these are stand alone in a case study or video diary style. This researcher was keen to demonstrate a way that film of individuals could form the basis of a facilitated discussion, in order to gain a better insight into an individual's life. This discussion could therefore be one taking place during consultations at policy making level or locally, by including the individual in the ongoing training and development of their own support team. This idea of a personal tool for consultation and action research is expanded on in Chapter 8.1.1

There were ethical considerations to take into account and these are covered in section 3.8 of this chapter. Additionally and specifically the PMLD Network (2011) have published a consent guide, which focuses on the need to involve family, friends, carers and advocates in decisions regarding consent to publish. This researcher was mindful of the Network's concern that,

'many other people do not know much about the lives of people with profound and multiple learning disabilities. This can mean that some policies and services are not inclusive of people with profound and multiple learning disabilities' (PMLD Network, 2011 p3).

Odyssey, the researcher's adult daughter, was filmed by a worker, who has supported her for a number of years. The worker's perspective was considered to have added objectivity. Odyssey was only filmed in short bursts, at moments calculated to be appropriate by her support worker. The filming took place in familiar surroundings, and only as part of her regular routine. In some ways what was not filmed was as important to the discussion.

It was considered that the use of focus group discussions would provide an opportunity for care workers to reflect on the impact of the VP agenda. Working daily in a structured environment, sometimes on a one-to-one basis, developed the workers' heuristic skills and experience of the target population. Additionally it was felt the environment of the day centre might demonstrate through its style, focus and delivery of service, the ongoing remit of the VP agenda.

Focus groups are widely used in health services, for example as a way of listening to local voices (Murray 1994, Gregory and Mc Kie 1991). Frey and Montana (1993) in King and Horrocks (2010) see them as more formal, more directive as they have a moderator who guides the discussion (p66). Whilst they can range from very formal to quite informal, the groups selected were fairly formal, as they were held at the work place, usually with the manager present. Blumer (cited in King and Horrocks, 2010) contends that this type of group is more valuable than a representative sample. Brought together to,

'discuss collectively their sphere of life and probing into it as they meet one another's disagreements, will do more to lift the veils covering the sphere of life than any other device that I know of' (p41).

According to King and Horrocks (2010) the mere fact of being part of a group discussion is more natural than a one to one with an interviewer. The data obtained can reveal a social and cultural context for people's beliefs. For example there was a high percentage of African/Caribbean workers in the groups and the discussions at each centre turned to the manner people with ID were regarded and treated in the Caribbean and in certain African countries. King and Horrocks (2010) also point out the manner in which a group discussion can have the effect of participants re-evaluating their position. Frey and Fontana (1993, cited

in King and Horrocks, 2010, pp 23-24) also describe triangulation as one of methodological reasons for choosing focus groups. It was therefore considered, the data, combined with the data from the one –to - one interviews, could lend methodological rigour to this doctoral study.

The research questions were devised to explore the research problem in as much depth as possible, in order to find ways to examine the aforementioned lack of philosophical fit. For example, in order to understand the extent to which policy is informed by a social model approach to disability, it was necessary to conduct a lengthy literature review. This was ongoing and fairly problematic. There is no concrete or tangible agreement, either locally or internationally, on just what PIMD actually is, or what it entails. Indeed the notion of ID itself is a highly contentious subject, with discussions ranging from the argument that it is a purely social construction, that there is no such thing as learning disability/difficulties (Goodley 2001, Williams 2006) to the other end of the spectrum, where moral philosophers argue that pigs and other animals would have more right to life than people with PIMD, if this right were based on their perceived levels of self awareness (Singer 1994). Arguably, the reason for the former view is the uptake of social model approaches to disability research, which deny any discussion of embodiment issues, especially with regard to capacity (or lack thereof) and dependence. Hence the opportunity to define PIMD is lost and the door left open for abstract philosophical ruminations. This thesis argues that neither approach is helpful for people with PIMD.

3.6 Sampling

See; Appendix D Family Carers, p261, Appendix E Day Centre Staff, p262

There were 34 care worker participants in total. This broke down to 11 for the OL group, 14 at IL2 and 9 at IL1.The participants at the inner London centres were overwhelmingly African/Caribbean female. (7/14 = 50%, 6/9 = 75% compared to 25% of the resident population.) The remaining staff were British Asian (1), Eastern European (1) and white British (7). The outer London centre was more diverse. 1 /11 African / Caribbean female and 3 /11 African males, (compared to 30% of the resident population.) The largest ethnic resident population in the outer London borough was Indian, (32%) although there was only one Indian member of staff at the day centre. The remaining 7 staff members were; 2 female (eastern European) 3 female (white British) 2 male (white British). The total number of participants was 49.

This included two focus group discussions conducted at an outer London (OL) day centre with 11participants and one focus group discussion conducted at a carers centre in OL with 5 participants. Focus group discussions were also held at a day centre in inner London (IL1) with 9 participants and at a second inner London (lL2) day centre with14 participants. Additionally semi structured interviews were conducted with a number of family carers. One family carer was interviewed in outer London (OL) and nine family carers were interviewed in inner London (IL).

Mays and Pope (1995) describe the use of purposive sampling in qualitative research. This involves selecting specific, identifiable groups of people who possess particular characteristic (in this case providing formal and informal care and support to adults with PIMD). Lawrence et al (2009) describe the use of purposive sampling of adults with ID and family carers in their exploratory study. Likewise, purposive sampling of participants for the interviews and focus group discussions was a deliberate attempt to gain as many views as possible, from people who had a deep intimate day-to-day knowledge of the target population (Brown and Kandirikirira, 2007). This meant the sample was controlled for three aspects; having experience of PIMD, through being a family carer or formal care worker and living or working in the particular inner or outer London borough.

The sample also presented a range of diversity in other aspects. These included, age, gender, race, length of experience, social class, etc. Gerson and Horowitz (cited in King and Horrocks 2010, p205) suggest this provides useful additional information about the effects of similar social change (here the VP policy) on different social groups. Different political parties led the two boroughs. New Labour in inner London and the Conservative party in outer London (see Appendix C: London Boroughs' Comparative Features, p260).

3.7 Recruitment

3.7.1 Formal care workers

Recruiting the care workers necessarily involved negotiation with various gatekeepers. The researcher was already familiar with both day centres in the IL borough, however locating the day centre in the OL borough involved a web search and phone calls to the local authority's Adults with Learning Disabilities (ALD) team. Initial phone calls and discussion with the day

centre managers led to face-to-face meetings at the three sites. The meeting at the OL centre took place swiftly, but there was a long delay in setting up the meetings at the two IL centres, mainly due to management availability. The managers at all three sites were enthusiastic about the research. The common response was an agreed desire to raise awareness of this population and their needs. The researcher was clear about her position as a parent of an individual with PIMD when she delivered a verbal overview of the project. This included the aims, methods and the time required to conduct the focus groups. Managers were also shown a sample Participant Information and Consent sheet (see Appendix A p257).

All three managers offered the researcher the opportunity to conduct the focus groups in their pre-set training slots. In this way it was considered most of the staff ought to be able to attend. It was also agreed that the discussions had a training element, since the workers would be reflecting on the way Valuing People (DH, 2001) concepts impacted on their practice. The only difficulties encountered were in the timing of these slots, although this was entirely due to the researcher's own caring responsibilities.

The OL day centre was designed and purpose built, to accommodate clients with PIMD, which is why they were selected. The two inner London centres IL1 and IL2 were slightly different, in that they do have some clients who would not be classified as having PIMD. However, those who do, far outnumber these individuals. The participants were therefore selected by dint of being rostered on shift, on the particular days the focus groups were held. Two of the day centres (OL and IL1) had the same staff at both meetings. The IL2centre had the most staff so the second visit was able to include those who had not attended the first meeting. This meant all workers at the three sites participated in the study.

3.7.2 Family carers

The researcher's insider status in the IL borough meant family carers could be approached directly. A number of families attended the local carers forum and were aware the researcher sat on the Learning Disability Partnership Board as the High Support Needs champion. They were also aware she had been instrumental with another family carer in convincing the Partnership Board to commission a report from Royal Mencap surveying the needs of adults with PIMD in the borough.

Notwithstanding there were still difficulties in pinning people down as it were. For example, the researcher would broach the topic informally at carers meetings, but the follow up was not always successfully arranged due to difficulties with convenient visiting times. The researcher additionally attempted to broaden the pool of available families by gaining permission from the local day centres and Specialist College for a mail out to families of all attendees. This was entirely unsuccessful as no one responded.

Of the nine carers who participated in the inner London borough, five regularly attend the Partnership Board meetings. This could be said to have coloured the findings somewhat, as these families were already involved and lobbying via their carers' forum, which feeds issues back to the Partnership Board and all had a working knowledge of the concepts of Valuing People (DH 2001). Only one of these families had never attended a Partnership Board meeting. It was also reported by all three, day centre managers that they had stopped running carers' groups due to lack of interest. This may reflect the older profile of some family carers and the full time employment status of others.

The Princess Royal Trust, have published a good practice guide for consulting with carers (Keeley and Clarke, 1999) in which they discuss '*harder to reach*' carers (p26), but only in a physical, rural context. The recruitment difficulties encountered by this researcher have demonstrated carers may be harder to reach, due to reasons other than location. As will be demonstrated in C5, carers often feel they are repeating their concerns but no one is listening or responding. This consultation fatigue can cause them to withdraw from participating. As will also be discussed in C5, the carers who were eventually interviewed have been caring for up to fifty years. Unlike the carers in the outer London borough, the carers in the inner London borough do not have a physical carers centre. They spoke of a virtual carers hub, but were concerned they had lost a strong ally in their last carers' development worker (CDW) who had recently left due to LA funding cuts.

Since the outer London borough does have a physical Carers Centre it was anticipated recruitment would not be too problematic. Initial phone calls and emails to the CDW were followed up with a face-to-face meeting. Unfortunately this worker left her post soon after and there was some delay before a new worker was in post. The process had to commence again. There was some initial confusion as the new worker arranged for the researcher to give a presentation to family carers of people with ID, but none of them were carers of

individuals with PIMD. However, these carers mentioned another local group of carers (of people with PIMD) who met at a different location.

After further liaising with another gatekeeper (this time a local third sector organization manager) an initial meeting was set up. The group met monthly and offered the researcher the slot of one of these meetings. This was considered a pragmatic solution to locating participant family carers in the OL borough. On the stipulated day, five family carers participated in the group discussion. One other family carer who was not able to be present, but who wanted to participate, was interviewed in her home at a later date, convenient to her.

The fact that the OL group were specifically a group of parents of adults with PIMD, made their selection much simpler. Not so in the IL borough. In order to ensure the research findings had a degree of reliability and considering the core focus was the issue of PIMD, it was essential to find family carers who supported people who fitted the criteria. This process therefore involved a degree of sensitivity when responding to family carers who expressed an interest in participating. Possibly confused by the newer definition of high support needs a number of family carers advised the researcher that their son or daughter had high support needs. However, when asked, for example, how their son or daughter expressed themselves they might answer, '*she speaks for herself'*. If it transpired that their son or daughter was able to also travel on their own, or if they were living alone in supported accommodation, the carers were deselected. The researcher explained to them that she did not want to confuse the issue by having family speak for their daughters and sons, if those people were able to speak up for themselves. For this reason three families in IL and two family carers in OL were not included in the interviews, despite their belief that their adult children did have high support needs. Equally, a day centre manager argued, that all people with learning disabilities could be perceived as having complex support needs.

However, this study was trying to hone in on the particular experience of individuals for whom communication is something we must interpret based on observation of '*informal intentional concrete gestures like pointing and reaching, grabbing, hitting out, some vocalizations and facial expressions'* and '*unintentional or pre-intentional acts like body posture and movement towards or away from someone or something'* and '*involuntary or spontaneous actions which may include, laughing, crying, smiling, self-injurious behaviour, throwing objects, rhythmic or repetitive acts, and seeking or avoiding attention'* (Downs, 1999, p302).

3.8 Ethics

There were a number of ethical considerations, which had to be taken into account. These were to do with the original research design, the data collection and the analysis and discussion. There were also additional issues of ethical concern, relating to the use of film of a woman with PIMD, who could not formally give consent due to her lack of mental capacity.

*'O cannot verbally give her views, but it is possible to make a judgement from her interactions and demeanour (*ACS, careplan 2009*).*

Section 32 of the Mental Capacity Act (2005) refers to the necessity to include a consultation with carers. Paragraph 2 (a), states;

'R must take reasonable steps to identify a person who— (a) otherwise than in a professional capacity or for remuneration, is engaged in caring for P or is interested in P's welfare, and (b) is prepared to be consulted by R under this section' (MCA, 2005, S32 p2a).

As the primary carer for this woman for thirty-four years the researcher has much experience of meeting the individual's welfare needs. She also has insight into the individual's communication and manner of displaying distress or unhappiness. Therefore it was possible to observe Paragraph 4,

' R must provide the person identified under sub-section (2), or nominated under subsection (3), with information about the project and ask him— (a) for advice as to whether P should take part in the project, and (b) what, in his opinion, P's wishes and feelings about taking part in the project would be likely to be if P had capacity in relation to the matter' (MCA, 2005, S32 p4).

This is an important point to note as it clearly acknowledges people deemed to lack mental capacity might be included in research as long as they have an identified consultee. This is also the network of individuals Nind (2008) refers to. The difficulties Boxhall and Ralph (2011) refer to, arise when individuals are living in residential care with no direct family involved only those who are paid to provide the care. As was shown, these people cannot act as consultee.

The remainder of Section 32 discusses aspects of research, which involve medical treatment, which do not apply to here. However, Section 33 (2) *Additional safeguards, was observed.*

'Nothing may be done to, or in relation to, him in the course of the research—

> *(a) to which he appears to object (whether by showing signs of resistance or otherwise) except where what is being done is intended to protect him from harm'(MCA, 2005,S33 p2)*

It should be made clear that the individual in question is totally blind and has no discernible awareness of being filmed or photographed. Hence the main ethical concern in filming her was not to film any instances, which might compromise her dignity, or indeed to show her in moments of distress.

The primary ethical consideration observed was the notion of non-maleficence, meaning obliged to do no harm (Thorne in Seale, 2004). In this sense the study adopted a Millsian or utilitarian awareness of the underlying philosophical ethics. This seeks to describe the consequences of the research based on cost or risk set against the benefit, as opposed to a Kantian deontological approach, which emphasizes motive. In the latter, the protection of human rights, such as self-determination, privacy and informed consent are independent of the consequences (Dean, 1996).

In other words, this study contends that any harm to the individual is outweighed by the benefits to the group. Specifically, the harm to the individual in the film (the consequence of the act of filming her) might be seen as her loss of privacy. However, this is outweighed by the benefit accrued in raising awareness of issues relating to all people with PIMD. While much deliberation about the value of research and the ethics of filming a family member with

PIMD appeared to justify the methodological approach, this does not mean it will be ethically appropriate in all circumstances.

The Mental Capacity Act (2005) provides further clarity. Sections 30-34 are concerned with research with people who lack capacity to consent. Section 31(paragraph 2: a) clearly states the research

'*must be connected with the impairing condition….*'

And (paragraph 3) the

'*impairing condition means a condition which is (or may be) attributable to, or which causes or contributes to (or may cause or contribute to), the impairment of, or disturbance in the functioning of, the mind or brain.*'

Both of these stipulations are satisfied here as the research is connected to the impairing condition i.e. PIMD, which itself is attributable to functioning of the brain.

Further, Section 31, (4) is key.

'*There must be reasonable grounds for believing that research of comparable effectiveness cannot be carried out if the project has to be confined to, or relate only to, persons who have capacity to consent to taking part in it*' (MCA, 2005,S31p 4).

In a discussion of social policy research ethics, particularly with reference to including users in the research process, Glasby and Beresford (2007) question just how ethical said research can be if it does not include service users in the discussion. Whilst they were not specifically discussing users of services who lacked mental capacity, this does raise questions concerning inclusive research. The Department of Health's (2009) guidelines for social scientists acknowledges the ethical approval processes required for people deemed to lack capacity to consent, appear to be discouraging researchers. Boxhall and Ralph (2011) argue the difficulties are tied to particular methodological approaches. However as noted they initially arise when the potential participant has no identified consultee.

This doctoral thesis is seeking to highlight the fact that the very specific issues relating to individuals with PIMD have not been fully accounted for in public policy. Therefore it seemed highly desirable for this group to be included in some manner, which might inform,

illustrate and provoke discussion. The over riding concern was to conduct the study with professional integrity. This included observing Social Research Association Ethical Guidelines (2003), Middlesex University School of Health and Social Sciences Academic Group granted research ethics approval in 2009 (see Appendix F: p263).

With regard to the design of the research, the ethical considerations undertaken were in responsibilities towards the participants. These included avoiding coercion, obtaining informed consent and maintaining anonymity, privacy and confidentiality (Social Research Association, 2003 pp 25-40). For those who actively participated in the study, it was considered necessary and appropriate to explain to them the nature of the research, the reason they had been selected and most importantly their right to withdraw from the study at any time, with no explanation necessary (Moriarty, 2011). In order to do this, the family carers in inner London (and one in outer London) were briefed by phone initially and also face to face. This was to provide them with as much background as possible to the study and also enough time to reflect on whether or not they wanted to participate or not. Additionally, a short presentation describing the study and its background was delivered to the group of family carers in outer London at their regular PMLD meeting, before returning to conduct the focus group.

On the day of their interview family carers were provided with an Information Sheet and Consent Form (see Appendix A p257). Verbal consent was also sought and obtained at the commencement of recording of interviews. It was further explained that any reference to their particular situation or specific responses to the interview questions would be anonymised in the writing up. There would be no reference to their real name or location. When they referred to their son or daughter, if they were quoted, they were assured the gender would be reversed. This was to reassure them there was no likelihood of their being identified in the final report (Moriarty, 2011 p25).

The day centre managers were originally briefed by telephone and in a later face-to-face meeting, regarding the focus groups with formal care workers. They then advised their staff, that in place of the usual training session, they would be attending the focus group discussion. On the day all participants were handed an Information sheet to read as they arrived. They

were also asked to sign the Attendance sheet/Consent Form (see Appendix B: p259). As with the interviews, before the recording commenced, everyone present was asked if they had any queries regarding the Information sheet they had just read. The reason for the research was then reiterated. This was followed by further confirmation that all discussion was confidential within the room and that the recording would be destroyed once it had been transcribed. If any direct quotes were to be used in the final writing up, the person would be anonymised.

Trust, empathy and rapport are all tied up in the ethical approach (Ryen 2004). One way to gain this is through self-disclosure (Dickson-Swift, et al, 2007). It was deemed relevant to explain to participants that the researcher was also the mother of the woman in the film. Explaining the reason for conducting the study and the reason it was considered ethical and necessary to include the film, added a dimension to the ensuing discussion. This disclosure enhanced rapport with the care workers and family carers by creating a '*level playing field*' (Dickson –Swift, et al p332). They recognized the researcher had insider status, that is, she understood the experience of caring for someone with PIMD, which in turn enhanced the researchers' acceptance by the participants (Darra, 2008, Corbin Dwyer and Buckle, 2009).

Reciprocity was achieved in the research process by sharing information. As the researcher is also a trainer in the area of ID it was possible to use the focus group situations to combine information sharing with the discussion. As an example, people had heard some of terms (e.g. social model, personalization, inclusion) but were not entirely sure what they actually meant, or what relevance they had for their client group. It was then possible to expand the discussion with an explanation. Some of the family carers had little to no knowledge of the main tenets of Valuing People (DH, 2001) so in the spirit of reciprocity this information was shared and expanded on.

Kvale (1996) points out the ethical dimension to representation of data, must include a reliable written account of that given by the individual being interviewed. The '*asymmetry of power*' (Kvale, 1996 p126) must be acknowledged. After all, the interviewer chooses the research topic and questions and guides the interview process. A way to balance this out is via a faithful representation of the carers' responses. This representation is backed up by the fully transcribed accounts from the recording, and again, one of the reasons a recording was considered appropriate. Hence the fidelity of the account is associated with an ethical

approach incorporating trust, which has been engendered by building a rapport with the participants. An ethical dilemma could be encountered in the writing up stage, in deciding what to include or not. In other words, only including the data that supports the argument, may not illustrate the full, lived experience the participants trusted the researcher to portray.

On later reflection, there were possibly moments where the researcher might have probed further. Judgements had to be made in situ, as to how much each interviewee was willing to reveal. Family carers expressed concerns that if they said too much it might affect the service their son or daughter received. This was expressed so often, it had to take on board as a real concern. This concern is backed up by the postings on the online Choice Forum (undated). This is a forum for professionals and family members, yet time and again the family members sign themselves as anon or anon parent).

3.9 Data collection

The purpose of collecting the responses was to analyse and compare them with the formal discourses inherent in the Valuing People (DH, 2001, 2009) policy. As this policy is framed within a social model approach to disability (Grant and Ramcharan, 2007 p77) and this study is a critique of that framework, it was necessary to obtain the data and give it a particular form, in order to then unpick the inherent meanings and critically evaluate them. As the literature review had demonstrated a need for clarity of definition (see C2.0, 2.2, 2.9) the data was needed to further illustrate this.

3.9.1 Critical discourse analysis

There was an initial analysis of the original VP white paper, which involved step-by-step, page-by-page scrutiny, in order to devise the interview schedule of questions. All of these related to promises within that document. Further analysis of documents including Valuing People (DH 2001), Valuing People Now (DH 2005), Improving Life Chances of Disabled People (DWP et al 2005), Estimated Future Numbers of Adults with Profound and Multiple Learning Disabilities (Emerson 2009), and Raising Our Sights (Mansell 2010) incorporated a hermeneutic approach. This method of interpretation is concerned with the meaning of the language used.

The convoluted explanations for independence are a prime example of the need for this method (for e.g. Valuing People Now, 2005, p16). The confusion over meaning is why this hermeneutic exploration was situated within a critical discourse analysis. It could then be argued that the examination of language, text, images and representations embedded within the policy, identified the social construction of target populations within said policy (Schneider and Ingram, cited in Fischer, 2003 pp 66-67). The CDA demonstrated the manner in which people with PIMD have been marginalized within policy rather than having their differences acknowledged. Fischer argues that the reason for this is because those very differences might well jeopardize the validity of the model (p99-100). The model being, arguably, the neo-liberal / welfare to work agenda, positioned within a social model approach to disability (see Burton & Kagan, 2006). By adopting an interpretivist analytical stance, the underlying issues and the manner in which they have been conceptualized could be examined.

Schwandt (cited in Denzin & Lincoln, 2003, p193) maintains that in order to understand a specific question it is necessary to grasp the whole, '*the complex of intentions, beliefs and desires of the text …*' . Shoen and Rein (cited in Fischer 2003, pp144-146) discuss the use of framing by policy makers, and the manner in which they reframe when expedient. Here again, the thesis explored the manner in which and reasons why notions of lifelong dependence have been reframed to better suit the agenda of independence. In order to further demonstrate this a four stage interpretive analytic framework was employed. Yannow (cited in Fischer, 2003, p141) argues that this approach shifts the focus towards social meanings and how individuals may have differing interpretations and assumptions about policy and its implementation.

Stage 1 required a semiotic focus on the research problem. The production of knowledge it is suggested, leads to emancipation (Wetherall et al 2001). Therefore, the clear use of definitional language and acknowledgement of PIMD was considered essential. The CDA identified that the language used within VP overwhelmingly represents individuals with ID as people whose impairment effects would be situated at the milder end of the spectrum.

Stage 2, involved identification of the obstacles to the problem being tackled. The confusion over exactly what is meant by the description PIMD was identified, as was the need for clarity about the manner in which the problem is represented.

Stage 3 sought to understand who benefits the most from the way social life is now organized, and who has an interest in the problem not being resolved? Interested stakeholders such as People First, Values Into Action and various supported living and social care providers were identified. Local Authorities' decisions regarding budget cuts in response to national coalition austerity cuts (especially to specialist services) and their ongoing outsourcing programme, were also identified. This included discussion of Individual Budgets (Carr, 2009) where service delivery is perceived as becoming informalised or voluntary.

Stage 4 looked at ways around these obstacles. In this case, by identifying the lack of fit and demonstrating, via critical reflection the manner in which the target group have benefitted or not from the VP agenda.

Using a CDA contributes to an understanding which explores ideology and power relationships. Further it is useful for uncovering ideological assumptions, for example the aforementioned Welfare to Work agenda of New Labour (DSS, 1998a) and latterly the coalition government's Get Britain Working agenda, in which everybody must be employed (Department for Work and Pensions, 2011).

3.9.2 Interviews

There were a number of considerations, which needed to be taken into account with regard to preparing for and conducting the interviews. Initial consideration was with regard to the type of interview. Should it be open ended or semi structured and conducted by phone or email or face - to - face? It was decided to make the interviews semi-structured as this incorporated the desired flexibility, without being too open-ended. It was anticipated that family carers may want to bring up subjects of concern to them and the researcher wanted the process to be adaptable enough to incorporate this. Whilst the formal interview guide comprised the same list of questions that were used in the focus group discussions (see 3.9.4), there was room to manoeuvre within this format, if the participants did want to discuss something tangentially. For example most interviewees digressed at some stage into a more personal account of some aspect of their son or daughter's life. It was noted in the researcher's diary that often it felt to

her as though people had a need to tell their story. In doing so they provided some additional illuminating insights.

It was decided not to use the film as a prompt. Initially it was going to be shown at the outer London carers group, but there was no facility available in the meeting room. Additionally, most of the carers interviewed in inner London already knew the woman in the film. As it transpired, it was felt the family carers were more able to engage with the discussion by personalising it with their own sons' and daughters' experiences. Participants were offered the choice of venue for the interviews and all the inner London interviewees chose their own homes, whilst as stated the outer London group chose to meet together as part of their PMLD meeting and one other family carer was later interviewed in her own home.

The Interview Schedule (Appendix B: p259) whilst essentially a guideline to prompt discussion, comprised a set of ten questions. As previously stated, these were derived from a systematic analysis of the objectives contained within the original VP document. This gave some structure, direction and focus to the responses for the later analysis. This would have been problematic if the interviews and focus group discussions had been completely open ended. The questions were also designed to give some background, i.e. the personal characteristics of the individual with PIMD. These included their age, gender, and types of services they received. They also covered areas of knowledge interviewees had of the VP strategy, or the social model approach to disability. There were also questions designed around the context of values and opinions. These were asked in order to gain some insight into how interviewees felt life for those they cared for had changed (or not) since the new strategy was implemented.

Formulating the questions by basing them on actual promises inherent within the VP strategy, stopped them being merely based on the researcher's opinion It also avoided the problem of leading questions and helped to avoid the interviews becoming too conversational. Face to face, the conversation was allowed to drift, according to the interviewees' preferred focus. The formal list of questions was used to bring them back to the subject. Prompts were employed, especially at the beginning, as an attempt to clarify for the interviewee what information was being sought. Probes (follow on questions devised at the time) were used in order to encourage further discussion. These were especially helpful during the focus group discussion with family carers in the outer London borough.

All interviewees verbally agreed to the recording, at the start of the interview. It was further explained to them that the recording was to ensure reliability, and in order to ensure confidentiality any actual quotes or references to their views would be anonymised in the writing up process. The recording equipment used was very small and unobtrusive. Permission was also sought to take notes, although this was kept to a minimum, in order to concentrate on building a rapport with the interviewees.

All interviews commenced with an opportunity for the participants to give some background life narrative, regarding their son or daughter's story so far. This was in order to gain helpful background information, but it also enabled me to build rapport with them. I built on this by revealing some of my own story. It was helpful for the carers who did not know me to recognize that I was familiar with the target population and had personal experience of the policy we would be discussing. All the interviews finished with the researcher asking if there was anything that hadn't been covered, either regarding the research project or Valuing People, which they would like to bring up. All the recorded interviews were later transcribed, along with additional reflexive notes made on the day immediately after the interview.

3.9.3 Filmed excerpts

The first film (Excerpt1) is 8mins 34 secs. It shows the woman inside her flat, demonstrating certain skills, which could be associated with 'independence'. These skills have taken four years to develop and have involved constant 1:1 support and constant staff development. The woman's Care Support Plan is entitled TIME and this film clearly demonstrates why. As an example, walking with the aid of her indoor cane, approximately six feet, from the living room to the toilet, with audio and vocal prompting, takes almost two minutes. Carrying a plate and later a cup, and following audio cues and vocal prompts, covering a distance of about ten feet, takes some three minutes. Neither task is actually completed. The reason for including these was to prompt discussion about notions of agency, training issues and additional support issues. These are all highlighted in VP (DH, 2001 pp 7, 14, 23, 44 and 90) and VP Now (DH, 2005 pp 9,10 and 116). It was anticipated workers would respond to this with thoughts on pockets of independent action or potential for independence islets, in spite of the individual's over riding state of dependency. In fact the participants focused their discussion on the health and safety issues they perceived, the degree of prompting (vocal and auditory) the individual needed and the time it took her to (almost) complete the task (C6.6).

Similarly a clip showing her attempts to follow auditory and vocal cues to complete a task (flicking a switch on the kettle) had the same response. The participants completely focused on their concerns with health and safety issues. Considering this occurred at all three sites it suggests this has been the subject of some rigorous training (see C6.6).

The clip used to portray choice was included in order to demonstrate lack of capacity to respond to an offer. This woman has extremely limited functional language (she possibly understands four words). Although all participants appeared to be listening and concentrating on the films, only one person out of the three sites observed, '*the individual doesn't understand words*.' This was because the support worker has asked the individual if she wanted to '*take the lid off*' the container she was holding. In response the individual handed the support worker her cane. This clip was referred back to a number of times throughout the discussion, especially when trying to hone in on participants' understanding of levels of capacity to make choices.

The second film (Excerpt 2), which is 10 minutes 52 seconds in length, shows Odyssey 'accessing the community'. This notion is a key concept of the new VP strategy. The particular outdoor sequence was included, with the knowledge that this can be a stressful experience for the individual, so filming was difficult and disjointed. However there were clips of her negotiating a walkway and later seated in the public area of a local arts organization. The researcher was anticipating this would open out the discussion with regard to accessing the community. Instead most participants were focused on Odyssey face tapping. This particular clip was filmed at close range, which did make the tapping obvious. Most people with PIMD engage in some kind of sensory-based self-stimulatory behaviour. The researcher was surprised at the intensity of concern people expressed for the individual's well being. This is further discussed in C6.5.

The researcher deliberately revealed nothing about the film or what it was attempting to convey at the outset. It was simply stated that the session would commence with a short film. Notwithstanding, it did also portray unintentionally ambiguous images, as evidenced by the responses. The subjective nature of these interpretations, were particularly highlighted in the later discussion, although no one interpreted the film along the lines of the aforementioned themes. This in itself was considered revealing. On another level the use of the film enabled participants to build a bridge between the policy speak formality of the questions and their real life implications. It is unlikely the discussions would have achieved such thoughtful responses had they simply been question led. Overall the use of the film was considered an integrated aspect of the focus group and yielded much by way of discussion.

3.9.4 Focus Groups

The day centre managers advised all participants that the discussion would take place instead of their usual training slot. In this way, the workers did not have to be persuaded to attend out of hours, and the target population was not compromised in any way. The outer London (OL) day centre, offered the use of a separate room. This is used specifically for staff meetings and training sessions. At one inner London (IL1) day centre, there was no suitably large room, so the dining / lounge area was used. The staff at the other inner London (IL2) day centre did not want to use the training room, as it was quite small, so the dining area was used.

Morgan (cited in King and Horrocks, 2010, pp 44-45) suggests 6-10 participants is a good size for a focus group, which was the average for this study. According to Morgan less than six means the group may be too small to encourage discussion and more than ten participants can make the group too large to control.

As people arrived, they were handed an Information sheet and asked to sign the attendance/consent form. They were verbally advised to ask any questions raised by reading the Information sheet. They were also additionally verbally reassured of the confidential and later anonymous nature of their responses, including the manner in which recorded data would be destroyed after the writing up stage. It was explained that the recording was to ensure reliability.

The recording equipment comprised a small Olympus recorder and a round flat table microphone. This is designed for group meetings and is quite unobtrusive. People did not lean into it for example, when they spoke. It was interesting to note, even though the focus groups comprised support workers who were very familiar with the target population, the use of the video diary seemed to focus the discussion very keenly. Indeed one senior manager discussed ways of using it further, for staff training purposes.

Macnaghten and Myers (2004), describe the differing styles a moderator might bring to a focus group discussion. There were moments when the researcher needed to be quite direct and interventionist, for example, when broaching the specifics of the VP agenda. People were asked directly who could tell or remember what the key cornerstones of the policy were. At other times it seemed more appropriate to hold back and let the conversation flow, develop and progress. (This is discussed further, with examples in C6). Macnaghten and Myers (2004) also discuss the empathy one may have for a particular group and indeed the manner in which

a moderator might introduce their own personal narrative to the discussion. It was explained after the showing of the film, and after the discussion had started, that the woman in the film was the daughter of the researcher.

The researcher also provided additional background information about her experience as a trainer in the field as a number of the inner London workers had attended these sessions previously. This encouraged the participants to understand that the thesis came about because of a vested interest in the target population. As one of the workers noted, '*we know you don't just talk the talk, you walk the walk too'*.

There was general consensus across all the groups, that people out there aren't usually interested. Time and again, when attempting to unpick what was meant by something, the response was along the lines of they (meaning policy makers) have no idea about this group of people.

The same set of questions was used for the focus groups as for the interviews with family carers. As stated earlier, these questions were derived from an initial page-by-page analysis of the original Valuing People (DH, 2001) document and based on stated objectives therein. (See Appendix B: 259). These objectives were described as two-tier, based on better outcomes for people with ID and better systems for delivering the outcomes. The eleven objectives were based on the key principles, namely, rights, independence, choice and inclusion. The questions were however, open ended and in line with the hermeneutic approach of this study, were intended to draw out individuals' understanding and experiences of these particular objectives. There were further questions designed to elicit participants understanding of various definitions used in the policy and more general individual attitudes and beliefs about the nature of PIMD. As with the interviews, these formal questions still acted as a guide, prompts and probes were used in order to further discussion. The aim was to encourage discussion between the participants. If people were not contributing they were encouraged, by either having the next question directed to them or via the probes. If a few people began to dominate the discussion, the question was referred back to the others, by asking if they would like to add something.

As there was a comparative element to the study, these probes were also designed to tease out any additional information the groups might proffer. For example, was it easier to access the

community in the inner or outer borough? What did the term 'accessing the community' actually mean? What did people do in the community and was this different across the boroughs? What about changing facilities; were there more or less in each area? Was staff turnover / retention higher or lower in inner or outer London boroughs? Did staff have comparable knowledge of VP and its principles, at all day centres? All of this information will be included in the later discussion in C6.

As was discussed in section 3.4 p74 no pilot study was conducted. This was a small-scale study with a small pool of available participants. A pilot study would have necessarily reduced the numbers of participants in the main study, as it would not have been possible to include those from the pilot. Apart from the element of surprise with the film elicitation a further aspect of the focus groups had been the quid pro quo agreement to incorporate information sharing. If participants had then arrived at the main study having this additional information, this would have influenced the findings (Teijlingen and Hundley, 2001). In retrospect undertaking a pilot could have improved the internal validity of the questions and prompts. Also it would have been useful to involve another family in creating filmed excerpts in order to better demonstrate the feasibility of this tool for consultation and staff training purposes.

3.10 Conclusion

This chapter has outlined the research problem, objective and process undertaken to answer the research questions. It has detailed the reasons for selecting a qualitative triangulated design and described the individual research methods of critical discourse analysis, semi-structured interviews and film elicited focus group discussions. It further discussed the ethical considerations, which had to be taken into account in the recruitment of participants, from the researcher's daughter, to the care workers and informal family carers.

The following chapters will examine the data this research has yielded and argue it has provided an insight into the journey from policy to practice.

Chapter 4 Critical Discourse Analysis

'If the constructivist [interpretivist] methodologies are preoccupied with the restoration of the meaning of human experience, then critical science methodologies are preoccupied with reduction of illusions in the human experience'. (Schwandt, cited in Denzin & Lincoln, 2003, p193)

4.0 Introduction

Previous chapters have examined the manner in which PIMD has been marginalized within accounts of disability. This has been ascribed to the general confusion of definitions, the prevailing use of social model approaches and possibly a political unwillingness to acknowledge the notion of lifelong dependency.

This chapter will critically examine the prevailing policy framework for ID in the UK. '*Valuing People: A New Strategy for Learning Disabilities for the 21ˢᵗ Century',* which was published as a white paper by the Department of Health in 2001. The updated refresher document '*Valuing People Now: a new three-year strategy for learning disabilities. Making it happen for everyone'* was subsequently published in 2009, '*to make that vision a reality* ' (DH, 2009, p7).

The opening section will commence with a short description of the political and economic context for the policy, which will be followed by an overview of the policy storyline, with particular reference to PIMD. Finally, the construction of a target ID population is examined via the use of quotes, narratives and good news stories, for evidence of inclusion of individuals with PIMD.

4.1 Valuing People: political /economic context

Following Thatcher's neo-liberal reappraisal of the Welfare State (see Hall in Rutherford and Davison, 2012), on election Tony Blair introduced his '*New contract for welfare New ambitions for our country*' (DSS1998a). This new contract set out a third age for welfare

policy in the UK. As Blair described it, the first age, was defined by the Elizabethan Poor Law (Concannon, 2005 p5), which was concerned with alleviating destitution amongst the deserving poor. The second age focused on alleviating poverty via insurance based, cash benefit systems. His new third age was to be defined by welfare reformation; the basis of which would be a contract between citizen and state. This contract would involve the promotion of opportunities and empowerment, rather than dependency.

The rhetoric of third way policy is primarily concerned with moving from the old idea of a passive recipient of welfare benefits to the active citizenship of paid employment. This is the goal, which may be attained by seizing the newly available opportunities for education and training, which will then translate into paid employment. This centrality of work to the new welfare policy leaves one in no doubt. The citizen has rights conferred by the state and in recognition the active citizen must take individual responsibility and participate in the labour market (Powell 1999). In this new welfare state the citizen has a moral responsibility to work. As the government paper Valuing Employment Now (DH 2009) states '…. *all people with learning disabilities can and should work'* (DH, 2009 p2). This paper was published the same year New Labour published the Welfare Reform Act (2009). Clearly the VP strategy was nested within the wider overarching strategy of welfare reform

. Ruth Lister (2011) argues that by replacing the term social security, which ensured security through social means, with means tested financial support for people of working age New Labour adopted the American style of social assistance. Changing the name of the Department of Social Security to the Department for Work and Pensions confirmed this ideological shift. Unfortunately, by focusing on employment as the route to wellbeing, those who cannot work are overlooked and somehow aligned with the enduring discourse of the feckless and work-shy, poor underclass.

4.2 Overview of storyline with particular reference to PIMD

VP (DH, 2001 p1) begins with a forward by former UK Prime Minister, Tony Blair. He draws a picture of people with ID as socially excluded through discrimination, with few life opportunities. He further claims that parents of children with ID '*feel abandoned by the rest of us'* (DH, 2001 p1). He wants this to change. He wants us to deliver his vision. The way he sees this being achieved, is by the community (local councils, the health service, voluntary

organisations and people with ID and their families) working in partnership with the government.

VP (DH, 2001 p10) outlines the manner in which the government's proposals are informed by ideas of citizen rights, social inclusion, choice and opportunities for independence. As discussed earlier these ideas have been demonstrated to echo at least three of O'Brien's Five Service accomplishments, namely respect, choice and community presence (Brown and Benson, 1992) and they parallel the primary goal of social role valorization (Race, 2003). They are also closely aligned to ideas of choice, control and independent living inherent in the social model approach to disability (Morris cited in Thomas, 2007, p99).

The document is constituted in managerial style, as a process of problem solving. Solutions are to be achieved via delivery of specific objectives (Fairclough 2000b). There are three main sections, the current situation and vision for the future, the objectives for achieving the vision and the final section, which outlines how this will happen. Each section is sub-divided into chapters. These are headed by a description of the problem and challenges to achieving the vision, based on the key principles of rights, independence, choice and inclusion (DH, 2001 p23).

The first point to note is the length. The initial two chapters are only 15 pages long; the objectives section is six chapters and 75 pages, whilst the final section, which deals with how the strategy will be delivered, is just two chapters and 13 pages. Considering the vision is so grand and the objectives so wide ranging, the delivery section does seem to be very short, comprising a discussion of the setting up of Partnership Boards and a few pages outlining a proposed revenue source to fund the implementation of the strategy.

This analysis is specifically pinpointing how VP accounts for individuals with PIMD, yet there is no mention of this group until Chapter 8, p100. Chapter 1, Figure 1 (DH, 2001 p15), does not even include their estimated numbers as a separate item on the graph. In fact, the authors have provided footnote definitions for severe and mild/moderate learning disabilities, but not for PIMD (DH, 2001 p15).

Chapter 3 appears at first to take this on board, although it does only refer to severe learning disability and complex health needs, not PIMD (DH, 2001 p40). For the purposes of this investigation, the difference is key and needs to be understood. An individual with severe learning disabilities (SLD) for example, may be able to exercise choice (real choice between

a number of items) they may have speech and a degree of language ability. Whilst it is unlikely they could read, they would be very likely be able to communicate via accessible language or symbols. However the nature of their additional complex health needs will undoubtedly impact on all of these.

Chapter 4 is keen to emphasise that '*all people are capable of making choices and expressing their views and preferences*' (DH, 2001 p44) and later in the chapter gives the impression that accessible formats are accessible to all (DH, 2001 p52 paragraph 4.30, 4.31). The impression given is that, with the aid of (an unstated form of) technology, people can access information. This may be the case for some people, but it needs to be made clear this is not the case for everyone. In fact accessible formats are only accessible to a particular section of the ID population. To state that assistive technology can '*improve cognitive functioning' (DH, 2001 p52)* is simply misguided. Assistive technology may help cognitive rehabilitation in cases of acquired brain injury (ABI), however this is not the same as congenital PIMD.

Chapter 7 (p77) 'Modernising Day Services' (DH, 2001 Section 7.75) states *'the needs of people with profound or complex disabilities will be carefully considered* ', but stops at that. It appears then, the authors recognise those with PIMD do have particular needs, but stops short of recommending they be met via specialist input or through some form of continuing training and development of the support workforce.

Finally, the specific discussion in Chapter 8 (DH, 2001 p100 paragraph 8.33) acknowledges that people with '*severe and profound disabilities'* will require specialist support and input from a range of sources. However, whilst every other chapter commences with the government objective, followed by sections headed Problems and Challenges and What More Needs To Be Done, this is not the case with this section. In other words it highlights their specialist needs, but does not explore the problems and challenges meeting these needs entails. Nor does it set out any specific government objective to ensure delivery.

The section is slightly confusing, as it commences with section 8.32 'People with Additional and Complex Needs' (DH, 2001 p100). Those included in this definition are itemized although there is no acknowledgement that people may have all of these conditions, i.e. people with PIMD. Section 8.33 (DH, 2001, p100) focuses on the additional health problems, while section 8.34 coyly notes these people may have difficulty communicating and may need the support of '*a family member, advocate or supporter'* (DH, 2001 p101). By using the word may rather than will, the impression is given that these difficulties are not set. The

PMLD Network (2011) has latterly developed the following definition. They clearly use words such as all and will to avoid any confusion.

'*Children and adults with profound and multiple learning disabilities have more than one disability, the most significant of which is a profound learning disability. All people who have profound and multiple learning disabilities will have greater difficulty communicating. Many people will have additional sensory or physical impairments, complex health needs or mental health difficulties. All children and adults with profound and multiple learning disabilities will need high levels of support with most aspects of their daily life*' (PMLD Network, 2011 p3)

The use of indistinct language is arguably, key to the overall policy storyline. It appears that certain aspects of ID have been radically downplayed. Hence the use of may rather than will. Fischer (2003) maintains this is a deliberate ploy to conceal any inherent paradoxes or tensions in the main thrust of the policy.

Hence across the entire document, there appears to be confusion about what PIMD actually is and a reticence to acknowledge the specific needs and financial implications of those needs, for this group. VP makes clear at the outset, that a range of people were involved in consultation over the year prior to publication. Unfortunately there is no indication in the list that any people with PIMD were present or accounted for, at any of these meetings (DH, 2001 p10). The document throughout, illustrates sections with quotes by people with ID, good news stories and narrative accounts. The only narrative employed to specifically illustrate these final sections, dealing with '*people with severe and profound disabilities*', is an account of the life of a woman Margaret, now deceased (DH, 2001 p100). Since the thrust of the narrative account provided describes her experience of long term advocacy, which '*gave her links with the outside world, meals out, long walks, a personal holiday*' (DH, 2001 p100) this will be further discussed in section 4.4.4.

4.3 The New Vision

The quotes illustrating the four key principles, which underpin the new vision of VP, are anonymous. The speakers use language, which evidences the desire of the document to promulgate a representation of the ID population as able rather than disabled.

For example,

' *All this can be done by believing people with learning disabilities can move on and be independent'* (DH, 2001 p23) and *'people with learning disabilities have been saying for a long time we can speak up for ourselves* (DH, 2001 p24).

VP could have included a small section discussing the implications of the new vision for people with PIMD. However the fact that they did not, suggests an unwillingness to acknowledge the fundamental difficulty the underlying framework of rights, independence, choice and inclusion, poses for people who are wholly and lifelong dependent. Indeed Valuing People Now (DH, 2009) specifically argues that to assume some people cannot live independently and achieve full employment

' *sets a ceiling on what progress can be made by individuals and by society'* (DH, 2001 p31).

In the very next paragraph it appears to make a more conditional statement by stating

' *for some people such as those with profound and multiple learning disabilities paid employment poses particular challenges, although it remains an aspiration'* (DH, 2001 p32).

One might reasonably ask, whose aspiration?

4.3.1 Rights

The New Vision's key principle of Legal and Civil Rights is illustrated by 'People with learning disabilities are citizens too' (DH, 2001 p23). The section discusses the right to '*a decent education, to grow up to vote, to marry and have a family, to express opinions, with help and support to do so where necessary'* (DH, 2001 p23). Unfortunately none of this has particular relevance for people with PIMD. All the help and support in the world is not going to enable an individual with PIMD to pass exams, to choose a political party to support, to engage in a sexual relationship and have children, or indeed to form opinions. There is no specific reference to human rights, possibly due to the timescale of publication. This has been rectified with the publication of Valuing People Now (DH, 2009).

This emphasizes

'the strategy is written from a human rights based approach' (DH, 2009 p8) and *'people with learning disabilities and their families have the same human rights as everyone else'* (DH, 2009 p16).

It also states the document was responding to the concerns set out in '*A Life Like Any Other?'* (JCHR, 2008 p8) The main concern raised by the Joint Committee on Human Rights was '*the lack of specific reference to human rights'* (JCHR, 2008 Paragraph 39, p19) in Valuing People (DH, 2001).

Neither is there reference to specific rights, such as the right to social welfare provision, (Dean, 2002) or the right to local specialist day centre provision, or to local specialist college provision. There is no mention of the right to trained support workers or to the range of specialist support, such as physiotherapy, occupational therapy, speech and language therapy, and psychological support, which the strategy acknowledges as being key to good outcomes for this group. Nor is there any mention of the right to provision of equipment such as wheelchairs, home adaptations or hoists. And there is no mention of the right to visual impairment aids, or hearing aids. This list is not exhaustive, just an indication of the range of support an individual with PIMD may need during their lives. Pawlyn and Carnaby (2009) in their handbook outlining nursing care needs of people with PIMD, describe the above and also include dental care, respiratory care, dysphagic support, continence support, specific implications of epilepsy support and nutrition and hydration support (Pawlyn and Carnaby, 2009 Section 2 Chapters 8-18).

Part three 'Delivering Change' (DH, 2001, p106) does state that the local Partnership Boards will need to '*ensure the availability of service options to meet people's assessed needs'* (DH, 2001, p106). However, the Boards are not statutory or strategic, so they have no power to agree what service is funded or indeed where the funding comes from.

4.3.2: Independence

The principle of Independence is illustrated by the quote '*All this can be done by believing people with learning disabilities can move on and be independent'* (DH, 2001 p24). Here again the use of language is designed to fit the policy storyline. By simply inserting the word

many, this statement would have been all-inclusive. By insisting on the use of the all-encompassing people, those with enduring high support needs are excluded. Insisting that everyone is equal and has the same hopes, dreams, wishes and aspirations, denies their biological and intellectual diversity.

Further, the use of statements such as ' *... the starting presumption should be a state of independence the starting presumption'* (DH, 2001 p23), suggests the authors have an agenda. Their independence discourse constructs all people with ID as being less impaired. VP has constructed a policy led or policy informed representation of ID, which represents all people with ID as being more able even though this does not tally with their own figures (DH, 2001 p17).

Most Local Authorities now only provide services to people described as having a substantial or critical need. VP clearly states, *'many people with learning disabilities need additional support and services throughout their lives'* (DH, 2001 p18). These people do not simply need more life opportunities. The reality is, these are people who need highly specialised input, at the level of health care, support and for lifelong meaningful activities. Pawlyn and Carnaby (2009) describe this as '*meeting complex needs through complex means'* (p348). By ignoring this complexity, the approach becomes less formalized and more reliant on informal (i.e. unpaid) support from families, friends and volunteers. Vague ideas directed to training for employment or voluntary work, do not best serve people with PIMD.

4.3.3: Choice

The paragraph discussing the choice principle, pointedly states; '*This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives'* (DH, 2001 p24). Unfortunately this is illustrated by the quote, '*people with learning disabilities have been saying for a long time that we can speak up for ourselves'* (DH, 2001 p24). The conflation of reference to PIMD and the use of a direct quote to illustrate it are deeply worrying. Was this simply a misguided placing, or was it an attempt to convey the idea that people with PIMD can literally speak up and therefore also self-advocate? After all the term speaking up has now become synonymous with self-advocacy groups (see for e.g. Lawton (2007).

Patently, all people with ID cannot speak up for themselves, nor can they make important choices and express significant preferences. The paragraph refers specifically to people with severe and profound disabilities, but appears to believe and gives the impression that, with the right help and support, they can make decisions about '*where they live, what work they do and who looks after them*' (DH, 2001 p24). It further states, '*We believe that everyone should be able to make choices*' (DH, 2001 p24). This statement is problematic and the use of the words believe and should are worrying. Believing does not always make something so. Choice is a very wide- ranging concept. Apart from all the different levels to choice making, there is the added notion of informed choice making (Bexley LDS, 2002). This is very pertinent to all people with ID. However, for those with PIMD, it is unclear how accepting /rejecting or indeed only rejecting, is actually making an informed choice.

The reason there needs to be such clarity is to do with individuals' front line care. This is why there is such a need for constant training and development of staff. Of course every effort ought to be made to ensure people have an opportunity to make choices, however small, but it needs to be recognised that simple top down, all- encompassing, statements are not necessarily helpful when working with more profoundly impaired individuals.

The section includes the statement, '*for too many these are unattainable goals*' (DH, 2001 p24). This is absolutely right. For many people with PIMD, these are unattainable goals and it ill behoves us not to acknowledge this. Better to '*adopt a stance of honest acknowledgment*' which recognizes '*a need for planned dependence*' (Pawlyn and Carnaby, 2009 p 348) rather than the overestimation of abilities that, for example, Bartlett and Bunning (1997) refer to in their discussion of the importance of communication partnerships for people with PIMD.

4.3.4: Inclusion

The fourth key principle of inclusion is accompanied by the quote, '*people with learning disabilities can live just as good a life*' (DH, 2001 p24). Undoubtedly this refers to the idea that '*We go to work, look after our families, visit our GP, use transport, go to swimming pool or cinema*' (DH, 2001 p24). The difficulty is that this does not take into account the need for specialist services which will not be automatically available in every area or borough in the country (Mansell 2010). For example the basic need for community changing facilities has resulted in the Changing Places (2011) campaign. This campaign has not been terribly

successful. A quick search of the site revealed no available changing facilities in the outer London borough selected for this thesis. The inner London borough had none either, although there was one in a neighbouring borough, at the Houses of Parliament.

Henley (2005) points out, there have been many and various policies over the last fifty years, directed to community integration for people with ID. Whilst they are all commendable, the vital question at the heart of integration, is whether to close down specialist services and rely on community resources or acknowledge the ongoing need for these services for certain individuals. It is unclear that VP has answered this question. It seems to be left to local Partnerships Boards to find ways to modernise their services. Hence, if the Boards are across all local authority and county areas, it is unlikely there will be any kind of coherent national day care policy, as envisaged by Henley.

The local Partnership Boards have been created in order to further develop joint investment plans, which will in turn deliver VP's objectives. There is clear direction in VP about the Boards' responsibilities (DH, 2001 p28, 42, 43, 49, 50, 51, 51,65,68,72,74,75,78,82,85,87,88,93,100,103,104,106,107,108,109,110,113,115,116,117,118 ,and 130). One of the main directives is that these will be a form of partnership working (DH, 2001 p8). It is intended that by people with ID themselves participating, this in itself will contribute to their social inclusion. Riddington et al (2008) have argued, however, that the fact that these local Partnership Boards do not offer the members (i.e. persons with ID) opportunities to direct strategies and resource allocation at a local level, (regardless of individual's ability to process information) demonstrates the limits to citizen/public sector partnerships.

Redley and Weinberg (2007) point out the additional inherent contradiction in recognising ability over disability and in promoting people's political empowerment and voice in the design of public services. To what extent, they query, can people (whose very entitlement to the services is their intellectual disability) be empowered according to a model of citizenship, which requires intellectual ability and independence? This holds particular resonance for people with PIMD.

4.4 Construction of target population by use of quotes, narratives and good news stories.

After the sections discussing the overall vision, the quotes become authored again. For some reason the quotes in chapter two do not have an accompanying name as they do in chapter one and from chapter three onwards. Part two of the document, (chapters 3-8) deals with *'Better Life Chances for People with Learning Disabilities'* (DH, 2001 pp 29-103). The themes of the accompanying illustrative boxes refer to the manner in which people might attain these improved outcomes, through employment, advocacy and personalisation. In fact some people have already had such success in their new ventures, they want to spread the word.

Unfortunately, the vast majority of the illustrations reinforce the socially constructed image of the target population as predominantly self-advocating. This is further confirmed by the overall policy objective in Valuing People Now (DH, 2009), which states,

'all people with learning disabilities can speak up and be heard about what they want from their lives –the big decisions and the everyday choices' (DH, 2009 p97).

Schneider and Ingram (cited in Fischer 2003, pp 66-67) discuss the manner in which policy makers employ this strategy, to constitute group characteristics, which better fit the application of said policy. As they further point out, this is also the reason for many policy failures. The VP policy is attempting to position people with ID within a distinct definitional category, which is ultimately at odds with the reality of the lived experience of PIMD.

4.4.1 Preface

The two-page preface outlines the manner in which the policy's proposals were developed. It points out that *'all the quotes are from people with learning disabilities came from consultation process'* (DH, 2001 p10, *sic*). This raises the question, were the only people with ID involved in the consultation those who were able to actually speak?

The later statement *'developing these proposals involved extensive consultation'* (DH, 2001 p10) refers to a number of key interest bodies. However, there is no listed body, which specifically represents the interests of people with PIMD. This may be because no such body

existed at the time. The PMLD Network (2011) was subsequently set up as a response to the developing concern that this section of the ID population have specific needs, which were largely ignored within the VP white paper .As they state on their website,

'the vision set out in Valuing people and the subsequent programme of action and new initiatives have largely failed to impact on the lives of people with PMLD. If we are going to 'include everyone' this needs to be a top priority in this next phase of implementing Valuing People' (PMLD Network, 2011).

The second page of the preface lists five key messages, which emerged from the consultations. These break down into a short description of what children with ID want

'*To be treated like other children, not seen as special and included in ordinary activities'* (DH, 2001 p11.4).

What parents of children with ID want;

'better advice, information and integrated services' (DH, 2001 p11.4).

What carers feel;

'they have a lifelong responsibility, want to be treated as full partners by public agencies, they need better information and support' (DH2001 p11.4).

There is a longer description of what people with ID feel;

'excluded, unheard, marginalised and forgotten. They want to be fully included, they want advocacy and direct payments in order to gain greater independence and control' (DH 2001 p11.4).

The fourth 'message', is not an account of how people feel or what they want, it simply states

'people with SLD and complex needs are more likely to receive poor quality services' (DH, 2001 p11.4).

There is no reference or footnote to explain further or corroborate this statement. As mentioned previously, this message is not specifically referring to people with PIMD. It is only by reading between the lines one can make the assumption they are being included here. Again, the unwillingness to spell out the notion of multiple is jarring. It is unclear who is reporting the poor quality of services. Is it the service providers? Is it the family carers?

Or is this self-reporting by those with severe learning disability (SLD) and complex needs themselves?

The commissioned reports from, the Service Users Advisory Group, the family carers working group and the Centre for Research in Primary Care make no specific reference to PIMD. Hence the question arises, as to why this group is largely ignored. If the document were promoting an all - inclusive approach, surely there would be evidence of this in the illustrative boxes.

The quote accompanying the preface states '*You should be proud of who you are*' (DH, 2001 p10: Eve). As it illustrates the extensive consultation, it is unclear why there was not a contrasting quote from, for e.g. a family carer of an adult with PIMD. After all, the footnote explains that family carers '*helped us develop the new strategy*' (DH, 2001 p10), yet there are no direct quotes from any family carers anywhere in the document. Even the chapter wholly concerned with '*Supporting Carers*' (DH, 2001 pp 53-57) has no direct quotes. The term family carers is mentioned three times as opposed to thirty seven times in Valuing People Now (2009). This suggests that family carer involvement in the later consultation was much increased, but does not explain why it was so sparse for the original.

The section '*Involving Users and Carers*' (DH, 2001 p 99) is illustrated by a service user's quote only. Certainly with regard to the quotes, the issue of PIMD does not arise. All of the quotes are positive and optimistic and all portray the underlying message of independence, and empowerment achievable through self-advocacy and employment. See, Ruby (DH, 2001 p47), Malcolm (DH, 2001 p47, Alan (DH, 2001 p49), Susan (DH, 2001 p50), Anna (DH, 2001 p64), David (DH, 2001 p70) Steven (DH, 2001 p85), James (DH, 2001 p87), Imran (DH, 2001 p93) and Wendy (DH, 2001 p99).

4.4.2 Themes

Quotes, narratives and good news stories are used extensively to illustrate the document's New Vision and the main sections (DH, 2001 pp 14-100). The majority of the illustrative boxes are focused on the theme of employment. For e.g. Connexions (DH, 2001 p44), Cambridgeshire (DH, 2001 p77), Steven (DH, 2001 p85), James (DH, 2001 p87), Imran (DH, 2001 p93) and Wendy (DH, 2001 p99). The rest are split between proselytizing (Dh, 2001 Liverpool Resource Centre, p63, Alan, p49), advocacy (DH, 2001 Swindon People First, p46

Ruby, p47, Macolm, p47 and Margaret, p100) and personalization (DH, 2001 Hampshire Social Services, p48, Susan, p50 and David, p70).

The emphasis throughout is on increased autonomy and self-determination. '*It's about time we had something for ourselves'* (DH, 2001 Gary, p14). The something, he refers to is presumably the new agenda. This will ensure amongst other things, the right '*to be as independent as they wish to be'* (DH, 2001 p14) .The use of the word wish is problematic for a discussion of people with PIMD, who are lifelong dependent and the document appears to have difficulty acknowledging this. Valuing People Now (DH, 2009) has included three case studies to specifically illustrate the themes of respite (DH, 2009 Kieran, p48), personalisation (DH, 2009 Joe, p52) and person-centred approaches (DH, 2009 Paul, p50).

4.4.3 Spreading the word

There are a number of examples of people wanting to spread the word about VP initiatives, because they have found the experience so empowering. Carol is a member of the self-advocacy organisation for people with learning disabilities, called People First. They were involved in Valuing People's strategy group. Carol talks about her pride in being part of the Strategy Group and hopes '*we can work together more in the future*.' (DH, 2001 p52). She continues, '*it means a lot to work with such a good team ………committed to supporting people in their hard struggle to lead Independent lives'* (DH, 2001 p52). Her group was developed into the National Forum of People with Learning Disabilities (2011), which '*works closely with Government at a high level and is listened to very carefully by Ministers* ' (NFPLD, 2011). It is unclear from perusal of the archived online minutes of Board Meetings, if there is any specific representation of people with ID who cannot self-advocate.

Further on a group of self-advocates describe their experience of speaking up to medical staff at a Primary Care Group Board. They recount in VP how they told the doctors and nurses '*We want you to explain and listen to us. We want leaflets with pictures'* (DH, 2001 p63). This is meant to illustrate the idea in this section that people with ID ought to have the same access to healthcare as the general population. Unfortunately it also conveys the idea the all people with ID, can speak up and understand accessible language leaflets.

Alan is described as '*a man in his 50's'*, who now lives in his '*own terraced house'* (DH, 2001 p49). It is unstated whether he has a tenancy agreement with a social housing provider

or private landlord, or a mortgage. He met someone, (it is unclear who, or how he met them) but this person was '*getting a Direct Payment and Alan decided, yes, that's for me. I like the idea of employing my own personal assistants who I could ask to do what I wanted when I wanted' (DH, 2001 p49)*. Clearly Alan can speak up for himself. In fact he is so enthusiastic about the personalisation agenda, he now '*gives talks to social workers and people with leaning disabilities about how to get a direct payment'* (DH, 2001 p49).

The use of a story about the performance company Heart 'n' Soul, to illustrate the section on Leisure and Relationships slightly contradicts the proposals. The section discusses including people with ID in ordinary leisure activities (DH, 2001 p80). It outlines the expectation that LA's will ensure their service plans encompass the needs of people with ID. Heart N Soul is an extraordinary group. They are well established, tour nationally and run their own nightclub, very specifically aimed for people with ID. It is their Club, i.e. segregated from the rest of the population. In this context it is unclear what point is being made, by including this story in a discussion about social inclusion (DH, 2001 p80). The point about Heart N Soul is that these people choose to segregate, in order to socialize together. Whilst all people with ID are welcome at their events, they do not specifically include people with PIMD. The website advises '*if you want to take part, please talk to us or fill in a form'* (heartnsoul, 2011). They are included under this theme as their constant touring international appearances and television series have done much to raise the profile of people with ID.

4.4.4 Advocacy

The section, which covers choice and control, is illustrated by more quotes by self-advocating individuals. Malcolm tell us,

'*The government has got to understand how we feel about these things'* (DH, 2001, p47)

and Ruby states

'*The (advocate) explains to me what I don't understand, what social services are talking about. If I didn't understand what the questions were, she'd repeat it and explain it. She was brilliant. Helped me with debts, had problems with money-still have problems. Calming me down when I get stressed, any problems I can tell her and she tried to help me. If I'm in bad*

distress I tell (her) and she tells me who to get in touch with. I never had anyone better' (DH, 2001 p47).

These quotes are meant to convey an idea about what advocacy can achieve for people. VP has written quite extensively in this section about citizen advocacy (CA). This is an open-ended form of advocacy, which is very suitable (though not exclusively) for people with more profound needs. It seems an opportunity was lost here, to illustrate the worth of CA for individuals who cannot self-advocate.

There is a very long illustrative report accompanying this section, concerning the achievements of Swindon People First, who were originally established in 1988. This includes a mention of '*consultation with people who don't use words to communicate'* (DH, 2001 p46) but no further elucidation. The report closes with a statement about how successful they have been in obtaining funding and notes they are *'in a promising position to build for the future'* (DH, 2001 p46). Unfortunately, they closed a few years later, due to their funding being withdrawn (Perrin, 2007).

Finally, there is the story of Margaret. It states, that she had acquired neither language nor formal signing skills, but nevertheless was '*very well able to make her wishes known'* (DH, 2001 p100). It does not expand further, so one must assume these wishes were discerned via her behavioural reaction to various events. For example, the story lists some of the things she enjoyed doing with the advocate '*she acquired'* after her mother died (DH, 2001 p100). Again, a question arises as to how she acquired an advocate. It seems unlikely Margaret sought out and retained the advocate herself. It also states, that '*she lost contact with her family when her mother died'* (DH, 2001 p100). Surely it's the other way around and the family lost contact with her. She had no formal language skills, therefore could not use a phone or write letters. How was she going to sustain contact with the family?

It is not particularly clear what Margaret's diagnosis was. The story mentions her enjoyment of long walks, so she had no mobility problems. There is no mention of additional health problems, such as epilepsy. Nor is there any mention of sensory impairments or autistic spectrum disorder. And although the story concludes with her death, there is no mention of any age related illness or impairments. All of these are associated with the document's definition of *'additional and complex needs'* (DH, 2001 p100). It is unclear why her story illustrated the section '*People with Additional and Complex Needs'*. Was no living person with PIMD involved at any stage of consultation? If so, why was their story not used?

The example concludes by telling us, the advocate was the one person, who was '*there for her*' (DH, 2001 p100) and was with her when she died. So this is really a story about successful long-term citizen advocacy. Although VP did specifically refer to citizen advocacy (DH, 2001, pp17, 27,45,46, and 47) there was opposition to this from self-advocacy organizations. They believe CA is an old style of paternalistic support, which is not in keeping with the social model approach. This is another example of a social model approach failing to accommodate people with PIMD. Some people do argue that '*everyone can self advocate*' (Lee 2010). However, when pressed for a breakdown of people attending their self-advocacy group, there was no one attending who could not speak up for themselves.

According to the VP policy author Rob Grieg, '*Under Valuing People Now, the Valuing People advocacy fund will change to focus on supporting advocacy to have greater impact, rather than pump priming new groups as before. The fund will pay particular attention to people at risk of losing choice and control in their lives, such as those from ethnic minority communities and people with complex support needs*' (JCHR, 2008 pp 87-88).

A 2012 survey of advocacy organizations revealed eighteen out of the eighty-eight who responded, provided citizen advocacy. Of those eighteen it was not revealed how many had clients with PIMD (Roberts, et al, 2012).

4.4.5 Personalisation

Personalisation is the new approach to providing social care and support (Glasby, 2001pp 36-42). No more service-led, this new system, can supposedly deliver support tailor made to an individual's need. This is possible via the provision of an individual budget or direct payment. The individual might then choose what support they need, how it is delivered and when they receive it (see for e.g. Alan's story DH, 2001, p49). The person receiving the support is considered to be at the centre of the process and in control of this aspect of their lives.

The difficulty with using words like choice, control and user empowerment in the context of services for people with PIMD, does tend to overlook the reality of increased family carer involvement in planning, management and day-to -day delivery of said services.

This has been highlighted by a number of providers e.g.

'There should be strong self-advocacy and family and carer support and involvement. We believe it is vital to involve family, carers and advocates in this process to ensure people are really able to tell us what they want and what works best for them' (Creative Support, 2011).

The examples provided by VP, tend to gloss over this detail and simply state, *'existing networks support the person receiving the direct payment… '* (DH, 2001 p48).

They also demonstrate the informalised nature of this new style of support.

The first example discusses how ' *a man, living with his parents, receives a direct payment to employ a support worker from an agency for short breaks. Breaks can be a few hours in the evening and weekend or longer* ' (DH, 2001 p48).

It is unclear if there is anything else in this man's life, such as attendance at a day centre or access to continuing education or training for employment. Therefore, it suggests his family provides the bulk of his care. It also states that he employs a support worker, but this could mean his parents do the formal side of employing and managing the staff. Clements (2011) has noted

'the disabled or older person (or perhaps more commonly his or her family carer) takes control' (Clements, 2011 p2).

The second example seems to confirm the shift to informalised services. It states that this man, *'wanted to move on from the day service'* (DH, 2001 p48). However, the direct payments only help in accessing leisure facilities in the evening. So what is he doing the rest of the time and who is providing the support? Is it solely his mother?

Both these examples were provided by Hampshire Social Services to illustrate their new flexible direct payments scheme. It is unclear if the men might have provided the statements themselves, had they been a part of the consultation. Therefore it must be assumed that this is further evidence of no people with PIMD being included in these illustrative narratives.

Another example is Susan. The report outlines the process by which her circle of support enabled her to live independently *'with a rota of support workers'* (DH, 2001 p50). Is this a good news story about a woman with PIMD? Demonstrating she was unhappy with her existing care arrangement, by *'actions, facial expressions, verbal responses and moods'* (DH,

2001 p50) conveys to the reader the profound nature of her ID. It is therefore confusing to read that '*her expressions and views guide how the money is spent, so she is in control of the money*' (DH, 2001 p50).

This may well make sense to people working closely with her. However, stretching the language to accommodate a discussion of her within this framework feels deeply problematic. To present her story in this manner, to a policy maker or commissioner, or to someone who is not acquainted with her, is highly disingenuous. It lays claims to capacity she clearly does not have. How can this be described as a person centred approach? Surely it is denial not acknowledgment? Is she really in control or are the financial decisions, ultimately made by her circle of support, based on their combined assumptions about her?

Finally, David's story is an example of an individual becoming known to services, after the death of his mother. He inherited the lease on the bungalow, so rather than being moved somewhere else, the LA was able to provide the personalized care package and his life was not further disrupted. Of course the inclusion of a reference to his siblings living nearby and providing '*emotional and practical support*' (DH, 2001 p70) hints that the arrangement would not be possible without them. The fact that he is also receiving '*some intensive support …… to improve his cooking and domestic skills*' (DH, 2001 p70) demonstrates the man is unlikely to have PIMD.

4.4.6 Employment

Employment is the most commonly occurring theme and is explored in a number of different ways. Whilst VP acknowledges all people will need training and support to work, it does not always clarify whether the examples stated are for paid work. James's story (DH, 2001, p87) focuses on the fact that he is being paid, although there is no reference to how many hours a week he works. This is the longest narrative and goes into great detail about what an income means to James; (not having to save up for weeks to buy a CD) the training he received when he started work (pictures on bottles for easy recognition of various cleaning materials) and the additional benefits employment provides (confidence booster, new friends and a sense of belonging). Since the story illustrates the section referring to supported employment, it would have been helpful to include the support he received or still receives on the job.

The fact that

'he says, that since he's been working it's really boosted his confidence' (DH, 2001 p87)

demonstrates this man is self-advocating and therefore this is not a story about an individual with PIMD.

Steven's story (DH, 2001 p85) does not include direct quotes. It is unclear why not. Perhaps his story reads better than he can express himself. Notwithstanding, it is a story of successful training, leading to long-term employment. Steven spent some ten years attending a local adult training centre. After a trial work placement, his job became permanent and he has maintained it now for a further ten years. Unfortunately no details are provided about how many hours a week he works, or if he gets paid. The fact that he attended an adult training centre suggests he may have a severe learning disability (SLD) but not PIMD. The difficulty with the use of good news stories, instead of published research, is that they are more often than not, impossible to verify.

Another good news story is used to illustrate the policy's argument that day centres are

'often institutional', *'limit contribution to social inclusion or independence for people with learning disabilities'*, do not provide *'opportunities to develop individual interests or the skills and experience they need in order to move into employment'* (DH, 2001 p77).

Further, these centres cost LA's £300M per annum to run. It is hard to avoid surmising that this cost may be the real concern at the heart of VP.

The story explains how a group of people with ID won a bid to *'keep vending machines in the local college filled'* (DH, 2001 p77).

Another group bid for a contract to *'keep the village tidy'* (DH, 2001 p77) but it is not clear if they won the bid or not. A partnership with another college was developed

'to provide a base and opportunities to participate in a range of courses' (DH, 2001 p77). The college is for 11-16 year olds, so again, it is unclear who is accessing the classes.

'A local charity funded a job coach, so people had opportunities for individualized employment' (DH, 2001 p77).

Extensive enquiries have been unable to establish if anyone actually did obtain employment. Notwithstanding, the good news being reported here is that,

'people no longer have to be bused into Cambridge to a large day centre '(DH, 2001 p77).

It is not known if the groups included people with PIMD. Nor is it clear if these people were being paid. Whilst ostensibly a story about employment, this story is really about opportunities to move away from formal services, such as day centres.

Wendy's story illustrates the section '*Involving Users and Carers*' (DH, 2001 p99). It is unclear why there could not have been an adjoining statement from a carer, of an individual with PIMD. After all, the section clearly advocates,

'the involvement of people with learning disabilities and their family carers in training and development activities' (DH, 2001 p99)

Unfortunately the opportunity is lost and the emphasis of the story is on Wendy's job. This involves teaching healthcare staff, about learning disability issues. Again, it is not clear if this is a paid or a regular position. Wendy is clearly a self-advocating individual and finds,

'Teaching Doctors about Disability is very powerful and I enjoy it' (p99). She also points out, *'getting the job in the first place was very difficult. I was lucky I had the right support* ' (DH, 2001 p99).

Anna's *'support team had difficulty in involving her in planning as she was lethargic, passive and difficult to motivate'* (DH, 2001 p64).

Her story is used to illustrate healthcare checks. The good news is that Anna was given a health care check, which revealed an underactive thyroid, diabetes and hypertension. It goes on to describe how the treatment of this, enabled her to

'become more involved and use her wheelchair less' (DH, 2001 p64). This in turn, enabled her to *'volunteer to help in a Children's Centre'* (DH, 2001 p64).

The fact that she did, demonstrates she is self-advocating and employed, albeit in a voluntary capacity.

Imran's story is another confusing item. It is meant to illustrate the manner in which local services might be more culturally competent and

'*meet all the cultural needs of their communities'* (DH, 2001 p93).

The story describes how Imran has gained in confidence and independence, since accessing a

'*community- based group for Asian people with disabilities* '(DH, 2001 p93).

It appears his cultural need was more likely his family's

'*concerns for his welfare'*, which '*made them reluctant to introduce him to activities outside the home* '(DH, 2001 p93).

Once attending, he gained

'*confidence and independent living skills'* (DH, 2001 p93).

And the happy ending is that

Imran now has financial independence through his skills as an entertainer' (DH, 2001 p93).

Once again, the story is about the outcome, i.e. Imran's newfound employment.

The VP authors discuss the place of evidence-based research to inform service delivery (DH, 2001 p90) and yet their own policy is built around good news stories rather than robust research.

4.5 Summing-up

This chapter examined the manner in which people with PIMD are represented within the VP policy. On close examination, it would seem mostly not. VP is eager to represent people with ID, as having been at the centre of the lengthy consultations. Their voices have been used to great effect throughout the document. The stories and accounts of various initiatives, by those people themselves, are wonderfully positive and certainly fit the represented idea of individuals achieving through empowerment. Unfortunately for a document, which purports to represent the entire experience of ID, it overwhelmingly represents people whose disability sits at the milder end of this spectrum. There are twenty-one examples illustrating this.

Over ten thousand people responded to the consultation, which informed Valuing People Now (DH, 2009 p2). This document includes photos of individuals to illustrate the various

sections. There are twenty-nine people portrayed thus and a further three who have PIMD and they were all alive at the time of publication.

Analysis of the overall storyline of the original policy document revealed scant reference to those with PIMD. Indeed they are not even mentioned until p100 of a 137-page document. The explanation for this possibly lies in the underlying social model framework. Using this approach it would seem the authors do not wish to refer to specific individual impairments or impairment levels. Except they do. There is a graph on p15, Figure 1, which describes the prevalence of ID in 1999. Oddly in the accompanying section, it states,

'*In the case of severe and profound learning disabilities ......*'

yet the graph only represents '*severe learning disability' and mild/moderate learning disability'* (DH, 2001 p15).

It has a helpful footnote explaining what these two terms mean, so it is unclear why PIMD was excluded. Perhaps the authors of the paper really do believe that people with PIMD, simply need '*significant help with daily living'* (DH, 2001 p15) which is their own definition of severe learning disability (SLD).

VP used extensive consultation with people with ID and illustrated the document with their own quotes and stories. Therefore it seemed appropriate to examine those representations more closely, in order to unpack the portrayal of people with PIMD. There is one possible example of a woman, still living, called Susan (DH, 2001 p50). She appears to have a severe to profound ID, but not apparently additional impairments. And one other woman called Margaret, who died some years before the policy was written, possibly had a similar diagnosis. This stark evidence of lack of representation needs to be acknowledged and questioned. After all, the consultations were lengthy and it is hard to believe no one present at these had any experience of people with PIMD. Where is their voice within this document? The appearance of Christian in Valuing People Now (DH, 2009 p32) is welcome, but it is unclear why no one similar appeared in the main white paper document. This lack of visibility echoes a theme of Gaffney's (2012) paper, which explores the manner in which current 'welfare dependency' narratives are '*airbrushing long-term disability out of the evidence'* (Gaffney, 2012 p22).

This chapter has highlighted the perceived unwillingness of policymakers to acknowledge the reality of PIMD, rather than their own constructed illusion. The next chapter will present the findings from the family carer interviews, which sought to explore the seeming mismatch between the formal policy discourse of VP and the on the ground understandings of those who care for adults with PIMD.

Chapter 5 Family Carers

How do family carers of individuals with PIMD make sense of the philosophical underpinnings of the current policy?

Whilst the last chapter critically analysed formal policy, this chapter will analyse data derived from semi-structured interviews with family carers of adults with PIMD. These carers are denoted consultees for their family member under the terms of the Mental Capacity Act (2005). In other words, their family members are deemed not to have the mental capacity to undertake the consultation themselves.

As this study sought to explore the perceived mismatch between the formal policy discourse of VP and the on the ground understandings of family carers, it was necessary to frame the interview questions around aspects of the VP agenda. Hence their responses were derived from questions concerning the overriding framework and concepts of VP, the strategy within the approach, (including the implementation and impact on their lives and those they cared for) and some discussion of the definitions used by VP (see Appendix B: p259). These accounts could then be set against the critical examination of key policy papers to illustrate areas of congruence and incongruence.

5.1 Sample participants

See Appendix D: Family Carers p261

The difficulties associated with locating and recruiting family carers have been discussed earlier (3.7.2). The purposeful sampling employed, resulted in a total number of 15 family carers. This included one focus group discussion conducted at a Carers Centre (5 participants) in an outer London borough. Semi-structured interviews were conducted with a number of family carers in outer London (1) and inner London (9). Carer anonymity was a feature of the process hence responses were coded within an initialling system known only by the researcher. Their responses were identified in the findings as being from an inner London (IL) or outer London Borough (OL). For example, ND:O is a family carer from outer London.

The sample presented a range of diversity in aspects, such as age, gender, race, length of experience and social class (Appendix E: p262). It was considered this would provide useful additional information about the effects of similar social change (i.e., the Valuing People agenda) on different social groups (Gerson and Horowitz, 2010).

There were 2 sets of married couples, four married but without their partners present, 5 single women and 1 male sibling. Three of those interviewed were Greek Cypriots, one was British Asian, one interviewee was African Caribbean, one was Greek and the rest were White/British. Ages ranged from late 40's to early 80's. Three of the four married interviewees described their partners as

'fed up with meetings' (EP:I), 'too busy with work' (HN:I) and 'he doesn't really understand English' (ND:O).

Of the entire sample, one sibling worked on and off, one married partner undertook occasional work and one ran their own business, with their partner. Two people were registered disabled due to their mental ill health. Both believed this was due to years of stress and worry in relation to their caring role.

The vast majority (ten), were past retirement age. Of these, five (all women, four single) but had spent their working life providing full time unpaid care to their offspring. All were concerned that Carers Allowance is not payable on retirement, even though they were all still providing significant amounts of care.

One family (both parents retired), were finding their move to managing a self-directed support (SDS) budget was *'much more work than we expected'* (EP:I). These parents are both in their mid eighties and use their daughter's individual budget (IB) to purchase a service from a local provider, rather than employing individual workers. However, they pointed out the scheme still requires much input from themselves and they are seen as the stopgap when no workers are available.

Another retired couple had recently relinquished the care of their son, due to the closure of the local residential respite facility. Nankervis et al (2011), in a recent comprehensive literature review on the subject of parental relinquishment of care, explored factors, which might precipitate such a move. Commonly they were severe disability, carer distress and lack of planned regular respite. This particular couple pointed out they would have been very happy to continue fulltime care for many more years, but only with regular respite.

Considering the cost of fulltime residential care for an individual with PIMD is in the region of £150,000 to £250,000 per annum, this appears an example of extreme financial short-sightedness on behalf of their LA.

Of the carers in the outer London borough, only one (BL:I) received a service from either of the two local specialist day centres. Her daughter had been attending five days a week, but this had been reduced to one day a week a few years earlier. (The managers of both specialist day centres in the borough confirmed they were oversubscribed.)

The following quote echoes the experience of the remaining families who explained that their son or daughter receives the new informal service.

'*When they closed the old place a few went to GM, some went to SN and then the rest, like my son, they are just in the community* (TW:O).

This was a rich sample, which managed to incorporate the local ethnic diversity of each borough, by including at least one African/Caribbean interviewee in the inner London sample, and one British Asian and two Greek Cypriot interviewees in the outer London sample. Carers may be reluctant to be involved in research, which will have no immediate or apparent benefits for them or they might be frightened to speak of matters they are unhappy about. Conversely they might be happy with the service they receive. However, those who were interviewed and who attended the group discussion were forthright in expressing their views. The findings presented focus on the majority view, which was not contested by the remaining families.

On reflection the researcher considered the reason carers in the outer London borough presented a uniformly negative picture was likely due to the local ongoing restructuring of services, which no doubt contributed to the pessimistic tone of the group discussion. Re-interviewing these carers might well provide illuminating insights into how those services have adapted to include those with more intensive and specialized support needs or not. The sample represented the variety of different families caring for people with PIMD as well as the diverse support needs of the people they cared for.

The Interview schedule aimed to explore the impact of VP on their lives and compare them with the formal discourse inherent in the VP policy. Also, as the literature review had demonstrated a need for clarity of definition, the data was needed to further illustrate this need. The interviews therefore sought to examine what concepts like choice etc meant for they people with PIMD they cared for.

5.2 Boroughs

The two selected boroughs, also provided an opportunity for comparison based on party political approaches to service delivery at local level, for people with PIMD. These were New Labour in the inner London borough and the Conservative Party in the outer London borough. This included items such as access to and availability of specialist health, therapeutic, advocacy and respite services. The local profile of those with PIMD could be ascertained via Carers Forums and Learning Disability Partnership Boards (including specific sub-groups). It was anticipated breakdown of numbers living with family in borough residential care or outer borough residential care could also be included. However, obtaining these numbers has proven problematic, as neither borough currently holds a register of people with PIMD.

5.3 Interview Schedule of Questions (see Appendix A: p257)

As stated, the initial CDA of the VP policy informed the schedule of questions. These were derived from a systematic analysis, which involved step-by-step, page by page scrutiny, in order to relate the questions to promises within the document. The semi-structured approach ensured carers set the agenda to a degree and enabled them to highlight the issues most pertinent to their own situation.

5.4 Semi Structured Interviews

Incorporating a semi- structured style meant it was possible to be flexible with the sequence of questions and responses. It also made it possible to obtain important additional data, which emerged whilst interviewees thought aloud, as it were. The researcher's background as a carer was an advantage here. Revealing certain aspects of her experience encouraged trust and openness from the respondents. Trust, empathy and rapport were all considered essential to this research process. The disclosure meant the interviewees recognized the researcher had insider status, as she understood the experience of caring for someone with PIMD.

It was also helpful for the carers to recognize the researcher had extensive knowledge of the policy under discussion. Many had little to no knowledge of the main tenets of Valuing People, so in the spirit of reciprocity, this information was shared and expanded on. All the interviews finished with the researcher asking if there were any aspects of the research project or Valuing People, which they would like to discuss further. All the recorded interviews were later transcribed, along with additional reflexive notes made on the day immediately after the interview.

5.5 Analysis

The interviews and focus group discussion were recorded verbatim. Notes were also made on the day about the general feel of the interviews. These were invaluable, as the researcher did not want to make extensive field notes during the interviews in order to focus attention on the immediacy of the interview situation. In the two earliest interviews there was some background noise, which made transcription quite difficult. However all the later interviews and focus groups were conducted with a new Olympus recorder and professional boundary microphone, which picked up all the sound very well, with no background hiss.

The transcription process was very time consuming, even with the use of a transcription machine. However, it meant that once all the data was typed out the researcher was extremely familiar with it. Addressing individuals by name as a cue during the group discussion further aided later identification. The focus group discussion with five family carers yielded ten (10) typed pages of data. The ten individual interviews yielded between two and six typed pages each, totalling forty-one (41) pages. Miles and Huberman (1994) have suggested three guiding principles researchers might adopt when analysing qualitative data. These are data reduction, data display and conclusion drawing/verification.

'*Anticipatory data reduction*' (Miles and Huberman, 1994 p10) occurred before data collection with the devising of research questions and the conceptual approach to the research. The next step involved a form of data reduction whereby the researcher worked through the data line by line and summarized comments in the margin. As an example GH's transcript started out at three (3) pages. The researcher summarized each response into one or two sentences and recorded these in the right hand margin of the page. This continued with all the transcripts. As the researcher worked through these pages, notes were also made and

cross-references highlighted where responses had similarities or differences. Also a note was made if the responses sparked a notion that linked to the critical discourse analysis of the VP policy. It was also noted if there was a statement, which refuted or confirmed something a care worker had said in their focus group discussions.

This led to an emerging data display, which necessarily excluded certain areas of discussion that did not relate to the research question. For example biographical details, which emerged were discarded at this stage. The list of interview headlines was used to assign the various response summaries. Different coloured highlighter pens were also used to aid identification of particular areas. These areas were eventually grouped as themes.

The final stage of this particular strand of the overall analysis involved decisions around which themes were the most common amongst all the responses but without neglecting isolated or unique opinions. This was the most problematic stage. It was clear there were common themes, but the concern was that individual detail or contrary positions would be lost in the reporting. How the individual carers interpreted the new approach to services was key. These concerns informed the ultimate selection and choice of quotes.

5.6 Emergent themes

The Interview Schedule comprised four loosely defined categories. These were, VP concepts, participants' knowledge of underlying philosophical framework, participants' perceived impact of VP policy and participants' knowledge of specific ID definitions. The transcribed data from participants' responses was analysed for emergent and recurring themes. The four emerging themes were, choice what choice, cost cutting exercise, consultation fatigue and PIMD overlooked.

5.6.1 Choice or what choice?

'We believe that everyone should be able to make choices. This includes people with severe and profound disabilities who, with the right help and support, can make important choices and express preferences about their day to day lives' (DH, 2001 p24).

The theme of choice was the most commonly occurring. Carers referred to their sons and daughters lack of capacity to make choices. Two families focused on the manner in which

they as parents made decisions, in the Mental Capacity Act's (2005) best interests style. Seven carers were concerned that staff did not acknowledge body language and behaviour as a form of communication. They believed the workers focussed on describing the behaviour as challenging, with no further attempts to understand or ameliorate. This was often compounded by high turnover of staff, including agency workers. There was also concern that an emphasis on minute, meaningful choice making was not being developed by support staff. These same workers were however demonstrating an overestimation of service users' mental capacity. Finally, there was an overall concern with the lack of choice regarding services or staff, which was supposedly one of VP's Objectives. (DH, 2001 p124)

Respondents simply stated their son or daughter could not make choices.

'All that is meaningless to him' (WD:I). *'She cannot. No. She doesn't do it'* (BL:O).

'He can't make a choice, we do the choice' (ND:O).

'My son cannot, no he cannot make choice; he is very severe learning disability' (TW:O).

Or, as one parent pointed out,

'if he don't like you he moans a lot, if he don't like what you're feeding him, he spits it out. I suppose that's choice' (UF:I).

One family described the way their daughter

'Cannot or will not make choices, except by body language, therefore we make the choices we think will be most beneficial and enjoyable for her' (EP:I).

This was one of only two families who had heard of the Mental Capacity Act (MCA) and who understood the concept of best interests (SCIE, 2011). However, families intuitively worked along these lines.

'It's how you approach them. This is key to everything. If you talk calmly and nicely, you can tell when he wants to do something ' (NN:O).

Expression of choice via body language and behaviour was expanded on by parents who were concerned staff ignored or misunderstood this.

'They keep telling me my daughter is happy, because she does this kind of grin, like a rictus grin when she's having a panic attack. She's not happy, she's very, very anxious' (GH :I).

'My daughter's behaviour is how she demonstrates choice, but they won't accept this. They're always reacting as if the choice she makes is wrong. 'Where are you going, sit down, come here, don't do that' etc etc ' (SB:O).

There was further evidence from the respondents that staff tended towards using the term challenging behaviour (CB) as a catch-all pejorative, rather than demonstrating any expertise in understanding what the behaviour meant.

'My son has challenging behaviour now from all the different workers. They said he pushed the TV over and this meant he didn't want to go out. My son is constantly blamed for his behaviours' (ND:O).

'With my son, certain people he's not accepting. These people are strong in their nature. If they were gentle, doing it calmly, he would let them. But they are in a rush and they know everything, so my son is blamed. They say he's very challenging' (TU:O).

There was a concern from some of the carers that offering choice too frequently might result in overloading and frustration for the individual.

'you can't keep asking him, he gets wound up' (ND:O).

Four of the five parents who participated in the discussion in outer London borough had a family member with an autism diagnosis, a physical/sensory impairment, ID and additional health issues, most commonly epilepsy.

'What you have to understand is they have the severe learning disability, they can't speak and they have this autism as well. It's really frustrating and confusing for them if you keep firing questions. I've seen the workers sometimes and they're all 'how are you today, what do you want to do now, where shall we go'. On and on. No wonder he lashes out at them. He just wants them to shut up' (NN:O).

This particular family (NN:O) felt their son had *'fallen through the net.'* There are two specialist day centres in the outer London borough. As they are very oversubscribed, those who don't have a place, have to attend the third centre. This place caters for a wide range of people.

'Its not all mild there, you know. There are some like mine, with the autism and all the behaviours and such, then there are others with very severe and complex health needs. Services seem to think if they go there they are more able, but many have just fallen through the net ' (NN:O).

This family is concerned that the staff only have a basic overview of ID and so are not well equipped to support those with more complex behavioural support needs. They appear to assume that because some of the service users are more able, that all of them understand to the same degree. Two other family members confirmed this.

'They're always on about how challenging he was at the centre. I think it just means he's getting on their wick' '(KX:O).

'Sometimes he makes these noises. They say in his book he was being challenging. I say he is trying to tell them something' (ND:O).

One parent pointed out,

'she's demonstrating choice, give her time. They're always acting as if the choice she's making is wrong. Saying, 'where are you going? Sit down. Don't do that' (GH:I).

Another was concerned about the way notions of choice were interpreted by healthcare professionals.

'He wouldn't let them do the blood tests, and they said that was his choice. Then later he wouldn't take his medication and they said the same thing, about it being his choice. So I asked them, when do they or where is the point that they take over? If my son won't swallow his medication and he needs it for his health, when are they obliged to do something? They couldn't answer me '(NN:O).

Question two had asked, 'how would your daughter/son exercise choice?' and overall the families had responded along similar lines, such as,

'he can't make a choice. We do the choice' (ND:O).

However, one family member in the inner London borough pointed out,

'we don't get no choice. What choice? You take what you're given, innit?' (UF:I)

This sentiment was echoed at the outer London focus group discussion, which suggests it was not confined to one LA. The focus group discussion in the outer London borough was very lively due to the evolving state of their service provision, which was being outsourced to two domiciliary care agencies.

'But we don't have a choice about who works with him' (ND:O).

One family had complained to their social services department, about declining standards at the home their son has been living in for many years. They were told,

'if you don't like it there are plenty of other people on the waiting list' (BL:O).

Rather worryingly, parents in the outer London borough, expressed concerns that they were being coerced into accepting what they considered were inappropriate support arrangements.

'The choice they are insisting we take, is this supported housing. I am fighting it. How can they say my daughter would be all right in a flat on her own? They tell me the warden checks on them maybe once a day. But my daughter wanders, she will fiddle with things like stick things in wall socket' (SB:O).

Another parent in the same outer London borough described a social services meeting where it was claimed her son had expressed a desire to move out of the family home and into residential care.

'On my son's report it said, he wants to go to a home. I asked them, how did he tell you that? He doesn't speak, he doesn't have the language. We demanded to see it in writing, that he never said that. You might feel he benefits from moving, fine, then say that. But don't say that my son said it. Then one lady said, 'I don't think he could have said that'. Because one person was supporting me, they all shut up. Before they were all shouting at me, all the time, that I don't trust' (TU:O).

This family are British Asian and expressed a strong desire to continue caring for their family member at home. They described what they felt was bullying by those present at this meeting. Whilst there may have been a genuine concern, to realize future accommodation for the family member (in light of the mother's deteriorating health) it appears no one was very culturally aware at that particular meeting.

There are a high proportion of British Asians living in this particular borough, yet none of the three families interviewed had ever been offered any culturally specific input or information regarding cultural diversity issues. Nor were they offered any advice about how to deal with staff if they believed they were being racist.

'A worker was so rude to me, because I wanted her to wear slippers in the house. I rang to complain, but I have had no response. Because I am on my own and yes, because I am Asian, they bully me. They think its alright to bully me' (TU:O).

Of the fifteen families, all but two were unhappy with the service /support provided. They believed this was due to workers' lack of understanding or training, regarding the specific needs and issues involved, when supporting someone with PIMD. Personal care concerns

were also raised by twelve (12) carers. They felt staff did not attend to grooming issues like manicure and pedicure, or to teeth cleaning and toileting. The workers' reasons were often framed within a rights /independence discourse. However the reality was that the care issues were being overlooked. This had ramifications such as one woman having recurrent candida because she was merely handed the toilet paper by staff, even though she had never learnt to wipe herself. As one parent explained,

'The carers (careworkers) won't do it, you know. I do it, because I want to keep his teeth. They say they are teaching them independent (sic) skills, but he will just hold his brush under the tap. The dentist keeps saying if we don't maintain his teeth, they won't see him even once a year. But no one else will clean his teeth. Only me' (TU:O).

The VP discourse of independence appears to have impacted negatively on care workers' expectations of those with PIMD.

'One of the workers told me I am too overprotective. She said M would be married now, if I didn't have her tied to my apron strings. She said they had just been to training in independence' (GH:I).

Six of the parents interviewed expressed the concern that they were seen as overprotective by service providers. They felt they were perceived as somehow holding their adult children back, or getting in the way of them achieving independence. This could be in conversation with support workers, who might say something like 'he always does it for me', or in the communication books that are sent home each day from the day centre. One family pointed out, it was the same account most days, and wondered who the book was for the family or the workers.

'According to the workers, he did so much when he was at that centre. I always felt I was doing something wrong, because he never did the same at home' (EP:I).

'They're always telling me he knows how to wind them up. They say it in a jokey way, but I know they really believe it ' (WD :I).

'There's too much about believing; you know all that wishes and dreams stuff. They sent home some form about it, I said she wishes people didn't shout at her and dreams of being left alone' (GH:I).

This parent went on to describe how her daughter would constantly strip off her clothes. This occurred more often when she was distressed.

'They keep telling me she's not stupid you know. She's very clever' (GH:I).

One family was happy with the support their daughter received, from their local Mencap organisation.

'They try to match up people they think will get on. Its worked very well so far' (EP:I).

This family described a long history of struggling to obtain appropriate services. Arrangements have broken down, to a critical degree in the past and they are now concerned, as Mencap had just been locally outbid and they are not sure if the new provider will exercise the same degree of matched support.

One family had relinquished care of their son when the local residential respite facility had closed with no replacement. Whilst they are happy with the placement,

'We do seem to be out there quite a bit. We expected that at first, but it's been pretty constant' (DX:I).

They are very clear that the placement needed to be with a specialist provider, but their choice would have been in borough.

'Of course it would be much easier if he was nearer home. You know, VP wanted more people brought back into borough' (NX:I).

This family pointed out that the concept of choice had apparently been taken too literally by some groups in the wider ID community.

'People were choosing to attend certain day centres or to live in intentional communities and these choices had not fitted in with the ethos of VP' (NX:I).

They believed this was why the concept was changed to control in the VP refresh (Valuing People Now, 2009). According to VP Now, 'control' means 'being involved'. '*This is about being involved in and in control of decisions made about your life'* (p16).

It is unfortunate that VP insisted on the phrase '…can *make important choices and express preferences about their day to day lives'* (DH, 2001 p24). The document would have been more inclusive and therefore resonated more with the families interviewed had it simply stated; this includes people with severe and profound disabilities who, with the right help and support, may express preferences about their day to day lives.

5.6.2 Cost cutting exercise

People interviewed believed VP was being used as a cost cutting exercise. The carers in outer London were concerned the new approach to services in their borough was more informal and impacted negatively on those they cared for. Three families (KX:I, BL:I, and NN:I) explained their son and daughters needed 2:1 staffing when they were out. This meant they rarely went out or if they did it was,

'round the block, go to the shops; they have to get back before he needs changing' (KX:O). Lack of specialist services was another concern raised.

'Some people don't have physio and they need it. They get it at SN. They have physio speech and language, hydrotherapy. The dental project, that's another. They go to SN, but not here' (NN:O). ('SN' is one of the local specialist day centres now oversubscribed).

The interviews were conducted in 2010 − 2011, so responses ought not confused with the later cuts to services, which were widespread as a result of the new coalition government's 'austerity' programme (International Business Times, 2013). Notwithstanding, carers in both boroughs reported a reduction in services and an increased use of untrained agency workers, which they believed was a symptomatic of a cost cutting exercise.

One family when pressed on the subject responded,

'there may have been some well meaning people feeding information into the department, in the consultation phase, but the overarching plan was always about cost cutting. Say, getting a life, or whatever it is they say, for most people with learning disability that means moving into the community, away from the day centre or into supported living, away from residential. Both are cheaper options'. (DX:I)

They agreed that, 'for many people that was appropriate, for those who could express their desire to live more independently that was a good thing' (NX:I).

This family feels the original aims of VP were distorted. As they pointed out,

'Rob Grieg (the author) was adamant the strategy was not about saving money However, if you point out to LA's, as he did, that there is a potential to save money, then they will adopt the strategy in order to save money' (NX:I).

Another parent described VP as,

'an ineffective policy, an excuse for cutting services. See all them, the pen pushers, the budget men; they don't want to spend the money. They spend it on all these new names, ah 'modernisation', but it was all just to cut services. That's what it looks like to me' (TD:I).

This does not tally with VP *Objective 9:*

'To ensure that all agencies commission and provide high quality, evidence based and continuously improving services which promote both good outcomes and best value ' (DH, 2001 p128).

It could be that LA's are focusing on best value at the expense of good outcomes. In fact, according to Sub-objective 9.4 they ought to be

'Ensuring people with learning disabilities receive best value from publicly funded services'

(DH, 2001 p129)

Sub- objective 9.1 suggests that Objective 9 ought to be achieved by

'Demonstrating that people with learning disabilities and their families are increasingly satisfied with services provided' (DH, 2001 p128).

Families in this study were far from satisfied with services, and believed services had gotten worse.

As one parent pointed out,

'by insisting on everyone moving to 'the community', there is a massive saving straight away. No need for day centre, staff or transport. 'Library' seems to be the answer for everything. They say we are going to have a Carers Centre in the library that the bases Jim Mansell talked about, are going to be in the library. Of course the library isn't built yet' (EP:I).

Carers in both boroughs attributed the move towards the use of agency workers, as detrimental to their son or daughter's care. One parent spoke about his son's alleged challenging behaviour,

'how can he ever get to know them? A different person comes every time. Sometimes twice a day. All different. Its a vicious circle' (TW:O).

Another was concerned,

'those staff, they don't even know about the epilepsy and they don't care' (TD:I).

A family who had tried to complain about the deteriorating service expanded,

'at first it was better. Some of the people were wanting to do everything right. Now they just don't care. My daughter's toes were bleeding, bruised everywhere, because they didn't straighten her toes before they put her shoes on. We sent all the complaints to social services, no response. When we asked about the broken wheelchair, they just say there's not enough money' (BL:O).

It is difficult to unpack the issue of LA outsourcing, through the use of external agencies. Whether or not this can be ascribed to modernization or latterly LA's own service cuts in response to the current central government agenda, is not entirely clear. What is clear from the responses is that none of those interviewed had any choice with regard to the support workers or transport escorts, provided. When pressed, no one had been involved in any consultation regarding the allocation of contracts, for example, for the outsourced services.

However, even with little understanding of the concept of personalisation for example, families intuitively wanted a person centred approach.

'You know, I personally think they should be having this kinda life, you know, here with us, with family, people who know 'em. Not locked up in some madhouse, away in the country, where we can't visit and all that. But saying and doing are, well that's another story. Cos, for him to go out, as I said, you need two people with him. See it's all this health and safety business now too. But mainly it's about cost. If they don't have the staff he don't go out, simple as that ' (KX:O).

Of the six carers in the outer London borough, three were actively resisting the more informal support options suggested for their family member.

'This is what I am saying. This is why I'm fighting it. It all sounds so good on paper doesn't it? She's independent, living in her own flat .... but what about the need for consistency, for good staff supporting her, who understand her condition. I know they all think we are overprotective, that we won't let them grow up. I fond that the most insulting, because we know, best of all, that they don't grow up. You can't change biology, or whatever it is '(SB:I).

Another explained,

'He used to go that day centre five days a week and now it's only one. The rest of the week it's supposed to be this new community life. But he does nothing. He goes nowhere. They just don't take them out. They tell me nothing; I've had him home for the last two months because of all this business with social services' (BL:I).

One of the parents, whose son displayed the behavioural support needs described as CB, was feeling the struggle.

'I'm fighting them, but sometimes I feel it's like walking through treacle. Do they care, do they want to know?'(NN:I)

Another carer questioned the new approach thus.

'They are saying this will be good for him, but we have to wait and see then. Like I said, it all looks good on paper, but... The centre's no great shakes. It's a bit of a holding bay really. Some of 'em can go out on their own or like a few of them with one worker. But my brother has to have two of 'em in case he has a seizure. I s'pose that's why he's only got two days allocated, he's more, well he costs more innit? . That's how they see it' (KX:I).

A British Asian carer who had been approached with the Self Directed Support option, was emphatic this was not something the family wanted to be involved in.

No, No, no. We don't want. I cannot do it. My son deals with a lot of my correspondence, but he is away, he travels a lot for his job. And my daughter is not in London. English is not my

first language, so how could I manage all that, all the paperwork and the staff. No, I cannot ' (BL:O).

All of the families interviewed recognised their sons or daughters incurred higher costs. This was because they needed 1:1 and in four cases 2:1 support. Indeed the inner London families had received notification at their Learning Disabilties Partnership Board meeting that those with high support needs (HSN) were compromising the savings Adult Community Services (ACS) were trying to make. Families were concerned that the new ways of working were designed to cut costs and this was reflected by the increased use of agency workers, who only had minimal training. This meant, for example, those people with CB issues were not receiving the quality of support needed to allay their behaviours. Or those who needed additional staff support when going out were being left behind. Families in the outer London borough were also concerned that the two specialist day centres were oversubscribed. This meant people without a place had to make do, at the remaining day centre. This was problematic for those with higher and /or more complex support needs, as this day centre catered for people who predominantly had lower levels of support need.

5.6.3 Consultation fatigue

There was a sense of 'consultation fatigue' amongst those interviewed. Carers felt they were constantly being consulted, but with no tangible results. They also questioned what power, if any they had. As illustrated in the quote below, people were concerned that the promises of VP had not been realised.

'It's all talk, talk, talk, but nothing happens. They use all these words. I don't know what they mean. I keep saying, I don't understand, English is not my first language, what do you mean?' (BL:O)

The outer London carers were concerned about the new direction services were taking. Unlike the inner London carers, however, none of those interviewed had ever attended their local Learning Disability Partnership Board. (The researcher attended two of these meetings and only met one family carer. He did not identify as the carer of someone with PIMD.) The carers at the group discussion reported that they felt it was for the LA and other officials.

'*They said they're going to reorganize the Partnership Board so we can have more influence. I'm not really sure what that means. We can say all we like, but is that influence*?' (NN:I)

These carers had attended various consultations but felt commissioners were not listening.

'One of their commissioners came to one of our meetings and we all told him about our experiences. He sat and listened, but he didn't write anything down. So what was the point?' (ND:I)

This parent was very concerned about the latest training for health care practitioners.

'Training has to be effective with demonstrated outcomes. Instead most is a tick box exercise, with no follow up, say in three months. It just looks good on cv's' (ND:I).

In contrast seven of the inner London carers advised they regularly attended and were very active on their own Board. Unfortunately, they didn't feel they had achieved as much as they anticipated at the outset.

'We were supposed to be getting better organized, more progressive services .... It's not jelling, not coming together' (EP:I).

All families interviewed in the inner London borough claimed services for this group were fairly limited.

'Not being funny, but what opportunities? The day centre and that's it' (UF:I).

One parent, whose son had attended a day centre on the outskirts of the borough, which included a separate respite facility, was extremely disappointed with the replacement.

'I remember when they used to talk about T and her hydrotherapy pool. We fought for the new day centre, we envisaged and we were promised so much' (EP:I).

The families in the inner London borough responded to the interviews in good humour. They would often comment along the lines of well, you know, as they were aware the researcher had a good understanding of their unsuccessful lobbying and campaigning. This was evidenced by their lack of local residential respite for over ten years. They also referred to how many changes there had been over the years, to the senior posts in their social services department. As they saw it people would come into post for a very short time, set certain strategies in motion, but not oversee them to completion. The carers felt the next person arrived in post with their own agendas. This meant they would start off on some new strategy or project, with no reference to what had previously taken place. This could account for the overwhelming sense of consultation fatigue.

'That bloke, what's his name, who promised he'd follow up that thing I was saying about you can't even take his BP, never mind blood. He was all talk. Now he's gone too' (WG:I).

Carers in both boroughs simply wanted good support for their son or daughter, which took into account their diverse needs. Pointedly, all thirteen parents expressed concern about what would happen after they were deceased. Whilst most had other family members, (brothers, sisters extended family), who they knew would carry on, there were two families who had no one. Understandably they were deeply concerned about leaving their children in a bad care situation.

'My biggest fear is what's going to happen when I die. All carers do a huge amount; they are heavily involved because they want to be, but mostly because we have to be (ND:O).

Another carried on, *'I worry about the ones who don't live at home. I spoke about this to social services, about who watches out for them when their parents are dead. As parents we fight tooth and nail but what happens to those without a parent?'*(NN:O)

When this parent brought up this subject, everyone joined in or nodded in agreement. The one sibling present expanded,

'when my mum goes on like this I tell her she don't have to worry. I'll take care of my brother' (KX:O).

One of the outer London carers had responded to the query about advocacy, by explaining, *'they don't want to offer anything long term. They don't like open ended. It's all got to be outcomes focused you see'* (ND:O).

This was why he believed the citizen advocacy programme had faltered. It made more economic sense for LA's to provide short-term advocacy, with a focus, be it a particular housing issue or health issue. The idea of open-ended long-term advocacy was, he believed, anathema to budget setters.

Carers felt that services were responding to the big ideas of VP, but in ways that did not make much sense for people with PIMD.

'They say they are preparing my son for the world of work. He's never going to work. I know that, they know that. With all the best will in the world, it's just not going to happen' (TD:I).

VP could have included a small section discussing the implications of the new vision for people with PIMD. That they did not, suggests an unwillingness to acknowledge the

fundamental difficulty the underlying framework of rights, independence, choice and inclusion, poses for people who are wholly and lifelong dependent. As one parent stated,

'It's always about what they are going to do. It's all what M is going to do somewhere in the future. All these new people. Every meeting there is some new senior person. They all come down and talk about what they are going to do. As soon as I hear that now, I just switch off. Oh, he's another 'going to' man' (GH:I).

5.6.4 PIMD overlooked

There was a strong sense from all of the interviews, that carers believed the specific specialist needs of those with PIMD were constantly overlooked. Not surprisingly this theme was therefore wide ranging. It revealed concerns around lack of respite, lack of leadership from managers, lack of training, concern with a one size fits all approach, a need for definitions, a feeling that carers' needs were low priority and unprepared transitions to adults services.

All parents interviewed in both boroughs described their difficulties in accessing respite. They felt the service was either non-existent or too ad hoc. None of the families had regular respite plans in place.

'well they closed that respite house when he was still at school and since he's been in adult services we've had no break. I dunno its gotta be ten years now' (UF:I).

No families, in either borough had respite needs included in their own carer's assessment that they were aware of. In fact, not one of the six carers in the outer London borough had ever had a carer's assessment. They advised that they were just hearing about them recently. On the other hand, the following quote sums up the experience of the inner London borough carers none of who believed their assessments achieved anything.

'I had it done right at the start … but you know it's in the small print, there is a proviso at the bottom of the page (he laughs). It's a get-out clause saying they don't have to do it if they don't have the money. So what's the point?'(EP:I)

VP Sub-Objective 4, did carry a Proposed Performance Indicator, seeking the '% of carers of adults with learning disabilities receiving community based services who are receiving short term breaks (DH, 2001p125). Unfortunately, since VP did not include a definition of short-

term breaks, the LA's make up their own. The carers in the inner London borough described how attending a carers' meeting counted as a break.

'Often, I have to take my daughter with me, as the times clash with when her worker's come. Or, when the workers are ill. I was shocked when I heard that counts as a break, even when she's with me' (EP:I).

Attendance at a day centre is now also being redefined as a short-term break for the carer, rather than a learning /leisure/ day opportunity for the individual with ID. In this way it is possible for the LA to claim 100% of parents of adults who are receiving community services, are in fact receiving a short-term break (JCS 2009 p19).

The inner London carers had lost their respite facility and this issue caused much concern. Indeed for one particular family, this had been the deciding factor in their recent relinquishment of care. When the site of the respite facility had been sold in 2003, their LA had assured them, that £2m would be set aside for a new residential respite service. With no prospect of this eventuating, the family had decided they could not carry on without regular respite.

The family believed their LA did not want to have the responsibility of staffing and managing a respite facility. In fact this LA now outsources the majority of their services and plans are underway for the outer London borough to follow suit. The LA maintains they are still offering respite services. However these are home sitting or informal holidays, which are not suitable for those with PIMD.

The family, who relinquished full time care of their son, explained they had been offered cover in their home, but their home failed a Health and Safety assessment. They were told people could not be expected to work with their son, without additional adaptations, such as installing bathing hoists.

'It was all right for us to manage all these years though' (NX:I).

They also saw the difficulty with being offered a basic home sitting service, as twofold. In order to benefit, the parents had to go away.

'This presupposes we have somewhere to go to or that we can afford to go somewhere. Sometimes, you just want to be able to relax in your own home. You have no idea how quiet this place suddenly becomes when he is away. There is a certain low gurgling noise he makes

constantly. It seems to echo through the whole house. Sometimes you just want a break from that (DX:I).

They were also concerned that the new informal short breaks in the home, would deprive people with more profound support needs from experiences outside the home. Other parents brought up the need for consistency being key to any service.

'My son needs structure; he needs to have a routine. You can't just suddenly say, offer him a week away to somewhere he's never been, with staff who don't know him. And then complain about his behaviour, so he never gets offered again (NN:O).

Thirteen of the families interviewed needed a specialist respite facility, which had the equipment (hoists, baths, beds) layout and staff necessary for supporting those with PIMD.

'There is no local suitable respite option for either of our children. The eldest has had 44 nights away in twenty-one years. Thirty nights between 16 and 18 years at a hospice in the country and 4 nights with another charity in another part of the country. None of this cost our LA a penny. This is a real problem and one we have faced all their lives. The money allocated for a 7-bed children and young peoples' service (CYPS) respite care facility in 2003, specifically for youngsters with PMLD /complex needs, was instead divided up between three local charities, to provide short breaks for a greater number of families. None of these were able to take either of our children. Now we find the same thing has happened in adult services, just as we come through from children's' (HN:I).

One of the sibling carers spoke about the lack of respite in terms of his mother's rights.

'I know they use those words, that Valuing People thing, huh …… I think it should be more about my mum's rights. She's on dialysis now three times a week. She's an elderly woman, she should get help. Look how long since we had respite. Others, there's others that are easier to manage than F; they go on outings, on holidays. Remember S took us to see that place? They expected to get F in a shower, that bloody toy shower. How were they gonna support him? It takes two people to lift him. How were they gonna get him from his wheelchair to that little plastic shower seat? It would have just collapsed. F's a big man and he can't support himself, he needs you to help him. All these ideas, they need to meet F, then they'd see' (WD:I).

This family has had no respite since before 2003. Apart from three sessions per week at the local day centre (10.00am till 3.30pm) they receive no additional input or help. Neither has the son been on any of the short breaks that were occasionally offered by the local Mencap service, as the accommodation was never suitable for those with complex support needs.

The family, who relinquished full time care when their local respite facility was closed, is happy with their son's current placement. However, they are surprised by how closely they still need to be involved.

'We do seem to be out there quite a bit. We expected that at first, but it's been pretty constant' (DX:I).

They are very clear that the placement needed to be with a specialist provider, which meant out of borough.

'Of course it would be much easier if he was nearer home. You know, VP wanted more people brought back into borough. They have brought back a few, but where is the specialist provision in borough?'

They are also clear that the quality of the placement is determined by the high quality of management and senior management within the organization. As they put it, *'without effective leadership you're lost' (DX:I).*

They explained *'When he first went there was a great manager. We could tell straight away, she was too skilled for the job. Sure enough she did get promote, she has a strategic position in head office. But you know, you can feel her influence in the house. It's in the way the new manager talks and the way the staff work. It's not empty words, if I can put it like that'* (NX:I).

Their comments chime with another parent, who feels he does not have the support from management.

'My daughter only has her behaviour to communicate, she doesn't speak, but no one is listening. Certain people just cannot get her to do things, so she's saying, she doesn't want them. When I tried to take the manager aside and tell them this, they just said, 'Oh I don't want to get into an argument on a Wednesday' (GH:I).

There was general consensus that staff needed to be better managed. Echoing the following participant, parents felt it was the job of management to guide and develop their staff, in order to enhance the quality of support they provided.

'I think at the day centre, they'd be happy if everyone just stayed in their wheelchairs. But, you know F can walk and they have the room there, they have that gym for a start, they can help him with his walking, but they don't. They'd rather just load him on the bus along with everyone else and just drive around ' (WD:I).

All families felt staff often did not have enough understanding or insight into the particular needs of those with PIMD. They were concerned that staff did not have any training specific to this client group. As they saw it, staff tended to try and control individuals rather than try to understand them. Support strategies or guidelines from specialist teams, such as speech & language or psychology were not followed. This was particularly the case where there were behavioural issues.

'There used to be a psychology team running the CB service. That's long gone. No one listened to them anyway. They all know better don't they? ' (GH:I)

'What is challenging behaviour? According to them, that's when F don't do what you want him to'. (WD:I)

'Sometimes my brother can cry out ...makes these noises, yes vocal, what you say? Vocalisations. They say in his book, he was being challenging. I say no, he is trying to tell them something. Maybe he needs changing, maybe he wants something, no no, not challenging. It makes him sound bad ' (BL:O).

The only family (out of fifteen carers) who were happy with the support their daughter received were also the only family using direct payments. Both parents are in their eighties, but since previous arrangements had failed they believed this was their only option. They believed the more informal support from a local provider suited their daughter. This family had removed her from the local day centre service and the education service, which had been brought into the borough, specifically for those with PIMD.

'When she started at the college, it was better. But they changed to this 'one size fits all' approach. They had a routine before; suddenly they were just taking them out to wander around the street' (EP:I).

This was the only family interviewed, who had opted for a Self Directed Support approach.

'She's better off with the arrangement now, because they always match the service user with someone they think they will get on with. Of course it's a lot more work for us, but she's happier, which is the main thing (EP:I).

A number of the carers were concerned that staff seemed to have had training in a new language. They often spoke of the new buzzwords, such as choice, independence, rights, modernization, accessing the community etc.

' same old same old as far as I can tell. They're the new buzzwords innit? Well H ain't never gonna be independent, she can't make choices, she don't have control of her body, or you know her bladder, never mind her life, and as far as I'm concerned she has the same rights as you and me ' (SF:I).

There was a concern that the one size fits all approach was not appropriate for those with PIMD. They believed staff used the new words, but that nothing had essentially changed.

' I don't know what any of 'em mean to be honest. They say he's got complex needs now. They used to say he was mentally handicapped and before that he was retarded. I just know he's my brother ' (WD:I).

One carer was concerned about the disability awareness training that had taken place recently.

'They did some project here, training the doctors about how to work with someone with learning disability. But they only did it with people with very mild learning disability. So, yes you have to explain things very slowly. But pictures are no use to my boy. And what about the time it takes for him to calm down or just get from the reception to the doctor's room? Doctors don't understand about severe autism and leaning disability, they think after that training, oh just talk a bit slower and he'll understand. Show him some pictures. It's not like that' (NN:O).

Another parent described the new paperwork staff had to produce.

'It's the new thing now, they all have a plan. It's full of all those stupid faces; you know, the happy face, the sad face. This is what she likes, oh and it's all in, you know, as if she wrote it. I like this, I like that. Who is it for? Not my daughter. It's just another way of avoiding her' (NN:O).

There was a concern amongst those interviewed that the new approach was very generalised. For example, the parents of those who attended the non-specialist day centre, in outer London were concerned people were missing out on essential therapeutic input.

'Some people don't have physio and they need it. They get it at the other specialist day centre but not here (ND). There they have physio, speech and language, hydrotherapy, they have it all there. This place isn't all mild, some like mine are very severe and others too. They have severe and complex needs. The dental project, that's another one. They went to those two

specialist centres but not to ours. Why not? Why don't they include it? They think if you go there then you are more able, but many, like mine, have fallen through the net (NN:O).

Another parent was concerned that the new way of working, meant services were getting worse, not improving.

'He used to go swimming constantly, now it's non-existent. You used to have a named social worker now it's all locums. They can't build a relationship, there's no continuity. See the nurse recommended these proper pads for him. We don't get them, and the next person who comes doesn't know what I'm talking about' (TD:I).

Carers were concerned that the new approach was too informal. There was an emphasis on 'accessing the community', but carers questioned what this meant. One parent felt

'these new initiatives, they act in a vacuum. Well, as an example, they want everyone in the community. Who do thy think takes him out all these years?' (ND:O)

Another family, whose son was still attending the local day centre, was concerned that the new way of working was not an improvement.

'They pick him up, take him to the centre. Unload them all, as far as I can tell, toilet them, change them and then it's time to get them all back on the bus again. They go somewhere like M, (another day centre) get them all off the bus. Take them inside for what? I dunno. Then pile them all back on the bus and back to the centre. All they seem to do is load them off and on that bus all day' (WD:I).

There was a concern from the carers in the outer London borough, that their sons and daughters were being shoehorned into inappropriate services.

'They have a block of flats, with a warden; everyone is in their own flat, on their own. The warden checks up on them, maybe once a day. But, look, my daughter wanders, she will fiddle with things, like stick things in the wall socket. She can't do anything for herself, like cleaning her teeth. I've tried to teach her for years' (SB:O).

Four carers (TW, KX, NN, and SB) expressed the concern that their sons and daughters had 'slipped though the net' regarding their day services. One (BL:I) was happy with the service but concerned it had been reduced to one day a week. Her son had been living in a local residential home for many years. He usually spent two to three days a week back in the family home. However, she was concerned that recently things had begun to deteriorate.

'At first it was better some of the people were wanting to do everything right. Now they just don't care' (BL:O).

When asked if she had been involved in devising his careplan she replied

'what careplan. He does nothing. Activities nothing, opportunities nothing. He doesn't go out. He sits in his wheelchair or they put him in another chair, he sits there all day in front of the television' (BL:I)

This is a small-scale study, providing a snapshot into the lives of a particular group of carers; with a particular emphasis on how they believe the VP policy has impacted on their lives and the lives of their daughters and sons. Whilst analyzing the data, reading and re-reading the transcripts from the interviews and discussions, it presented a worrying picture. After all there were only six people interviewed in the outer London borough and estimates suggest there are at least eighty (80) people with PIMD (Emerson, 2009) living there. Of those according to the borough's statistics, over 50% are placed in residential accommodation outside the borough. That still lives at least thirty (30) families unaccounted for. Families who do not attend carers meetings, either the general meetings at the carers centre or the specific PMLD group meetings at the local third sector organization. Nor do they attend the Learning Disability Partnership Board meetings. This raises questions such as is this because they are happy with the services they receive or disaffected to the point of non-engagement? Or, is it perhaps because many of them do not have English as a first language. VP Now (DH, 2009) highlighted this group as experiencing *'insufficient and inappropriate services'* (DH, 2009 p36). Considering the group interviewed for this thesis, comprised three (3) Greek/Cypriot and one British Asian out of six people, it is likely there are more such carers and they may not be well informed.

During the individual interviews one of the families questioned if the authors of VP had ever met someone with PIMD.

'Do you really think that lot who wrote Valuing People have ever met someone like my J? Maybe they think LD is just mongols, yeah Downs. And maybe there are people who can be independent and all, but not ours. That's never gonna happen' (UF:I).

Another family member believed policy makers were aware but chose to ignore because of the cost implications

'I think it's, well you've seen it here, they don't want to acknowledge our lot, cos they're too much in terms of cost. You saw it on that last form we had. They used a picture of people with

PMLD and said that was why they hadn't made bigger savings, cos this lot were expensive to support. They don't fit the bill. All that getting a job and into the community malarkey, that don't work for our lot' (WD:I).

There was no direct question about costs, yet all of the families in the outer London borough (6) and seven (7) of the families in the inner London borough brought the subject up. They believed this was why specialist services were lacking.

'Early 2001-2002, she was having three of four sessions of physio. Then you had a review with the doctor, the physio, the social worker all the professionals were there. Not any more, its all stopped' (TD:I).

Another parent, whose son had only recently transitioned to adult services at 24 years of age described her feelings thus.

'I'm shell shocked. I know that's what everyone says, but it's the best way to describe it. They knew my son was coming, they've known for years, so why were they so unprepared? (HN:I)

When asked why they thought VP only used the term SLD and if they believed there was a difference between severe intellectual disability and profound intellectual disability, one parent answered,

'My understanding is that although there is some overlap between the two terms, generally they say rather more about the experience of the person using them than about the individual' (EP:I).

At the group discussion in outer London two of the parents pointed out the LA wrote SLD on forms, but in conversation described their sons as having PMLD, because of their additional sensory/physical impairments and complex health needs. Their Learning Disabilities' Partnership Board plan refers to the VP agenda and the need to prioritise support for those with complex needs. However their plan only refers to people who need palliative care and is to be led by the dementia group, with no time scale for measuring outcomes.

None of the carers were clear about what VP meant by the term complex. This is understandable, since VP was not very clear itself. Whilst the document does itemise a number of additional needs people with ID may have, such as autism, epilepsy and challenging behaviour, it does not include a specific definition for PMLD (or PIMD) Indeed the small section that does discuss these additional complex needs is wholly concerned with health needs (DH, 2001 p100).

When asked to describe complex needs one carer pointed out,

My mum, me, and F, we all have complex needs. I think it should be more about carer's rights. What about my dad, he's on dialysis three times a week now. I have depression; we all take care of each other and look after F as well. It's been years since we had any respite. Others, like, there's some who are easier to manage. They go on outings, they get the holidays, but F needs special hoists and beds with sides. They took us to see some place; they expected to get him in this tiny shower space. How? How were they gonna get him out of his wheelchair and onto this plastic chair they had sitting in the shower cubicle? It's too hard so they just give up. We can't though can we?' (WD:I)

The VP definition of complex includes people with PIMD who have additional sensory/physical impairments. One parent advised,

' It's been over ten years now and still no word on the deaf/blind register. I asked the new commissioner and he didn't seem to know what I was talking about. This is supposed to be common knowledge now' (NX:I).

Worryingly carers believed they received fewer services, because they were living with the family member. This does echo the findings of The Royal Commission on Long Term Care Report, by Professor Sutherland in 1999. This found that those still living with family carers were seen as low priority by their LA. There was a concern from all of the carers that they were left to get on with it. During the discussion with the group in the outer London borough, when carers raised this and the researcher queried if others felt the same they all nodded and smiled in agreement.

'Well it's my mum really; she's the main carer, bottlewasher and nappy changer. She's got tired of the constant battle for any support, so she just gets on with it. It's like, she's been doing it so long, it's all she knows' (WD:I).

(This is the sibling describing his mother who is in her late eighties and who has her own severe health issues now, including kidney disease).

'Not being funny, but what opportunities are they on about? The day centre a couple of days a week and that's it. And you know she didn't even go there most of last year, well over nine months, cos they hadn't got her wheelchair sorted. Nothing happens unless you lose your rag. It's all bullshit ' (UF:I).

Whilst there was much discussion of the period of transition from child to adult services within VP, there was no acknowledgement of the various transitions, which can occur throughout one's adult life. Chapter 3 in VP discussed the setting up of partnership working, including good transitions into adult services. It specifically referred to

'the growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood' (1.10, p16) and yet, over ten years later,

'moving into adult services was like falling into a gaping black hole. Why did no one know we were coming'? (HN:I)

This family carer of two young adults with PIMD was describing her recent experience. This chimed with the Hirst & Baldwin (1994) study, which found evidence of inadequacies of services only becoming apparent at the time of transition.

At first this carer was unsure about contributing to this study, because

'as reasonably articulate, educated and older, therefore confident parents, we made a definite decision to have children some years into our relationship. We felt reasonably secure emotionally and materially. It never crossed our minds that our children should not be valued by others. So far we have sought and mostly received the best on offer from all medical and allied care professionals. Yes we have had to meet crisis after crisis these last 20 years or so, but we managed somehow. This transition experience to us indicates the extremely low priority that appears to be given to those with the most acute needs' (HN:I).

All of those interviewed expressed the view that no one seemed to be listening to their concerns. The respite needs of those in the inner London borough did not fit the new non-residential options, so they had none. One family had had no respite since before transitioning to adult services, as the children's respite centre had also closed many years previously.

The increased use of untrained agency workers was seen as detrimental to the well being of their sons and daughters. As was the move, especially in the outer London borough, to accommodate and provide day opportunities within a less structured environment. Carers were unsure what the various VP definitions meant and also felt many workers used the words, without really knowing what they meant either. They all believed strongly that as carers of people with PIMD, their needs had less priority in the eyes of local commissioners

or within government policy. And the carers of those individuals most recently transitioning from children's' services were dismayed by the lack of LA preparedness.

5.7 Discussion

The numbers of people with PIMD are relatively low at an estimated 78 per 250,000 (Emerson, 2009). Unfortunately this factor seems to work against them, when it comes to service planning. The new one-size-fits-all approach, promoted by the VP agenda, may make economic sense to LA's, unfortunately in real terms it means those with the highest need may be missing out. Family carers of individuals with PIMD, work long hours over many years. They represent enormous savings to LA's. Since there are relatively few people with PIMD, as a proportion of the adult population, or even the ID population, it would seem to make sound economic sense to properly support these carers, so they might carry on their role as long as possible.

The carers in the inner London borough appeared more informed about the processes being undertaken by their LA. They had strived for and finally achieved a PIMD sub-group on their local LD Partnership Board. They were concerned, however, that in the coming months and years gains in raising awareness of the specific needs of this group were going to be lost.

On two visits to observe the outer London LD Partnership Board, there were only two family carers present. Neither of these were carers of adults with PIMD. The reason for this may be because the families are happy with the services they receive, whereas those in the inner London borough are still lobbying for services. It could also be because most carers of adults are older themselves and as previously suggested, may be tired of the endless rounds of meetings and consultations.

There is also a higher percentage of British Asian carers in the outer London borough, which may mean language difficulties and cultural issues are another reason carers are not so visible. Older carers and those from ethnic minorities were flagged up by VP Objective 4: 'Supporting carers' (DH, 2001:125). Since most of those interviewed were older carers and a number were from ethnic minorities, their responses suggest this objective is not being entirely met.

Whilst there were no objectives or targets, within VP, specific to services for people with PIMD, there were general assurances. Chapter 8: 'Quality Services,' states at the outset, '*The government is committed to raising standards and improving quality in services for people*

with learning disabilities' (DH, 2001 p97). Why then do so many of the carers, specifically of people with PIMD, feel this has not happened? For example, many of the carers interviewed were very concerned about the lack of physiotherapy. VP specifically refers to the '*need to access physiotherapy, occupational therapy and speech and language therapy and orthopaedic services'* (p100). However, since there is no associated Objective or PPI target, there is no pressure on LA's to demonstrate how well they are delivering any of these services.

5.8 Summary

Over and again interviewees referred to lack of choice, lack of respite, lack of trained staff, lack of management leadership, lack of appropriate services and lack of planned transitions. The most prevalent themes to emerge were choice, cost cutting, consultation fatigue and PIMD overlooked. Families described their sons and daughters inability to make choices and expanded on ways they interpreted body language and behaviours to make decisions for them. Those families with experience of ASD issues raised a concern that workers lacked awareness of associated behavioural support needs. Other families felt workers missed opportunities for encouraging meaningful moments of choice making. Many families reported a lack of choice of worker or service. Only one family reported satisfaction with their service provision.

There was no specific interview question referring to cost or cost cutting, yet every respondent brought this issue up. Those in the outer London were in the process of having their local services incorporated into an outsourced one–stop shop. The families whose sons and daughters were newly transitioned to adult services were concerned this meant they missed out on community outings and vital therapeutic services.

All carers to varying degrees reported their concerns remained unheeded. Those in the outer London borough had never attended a Learning Disability partnership Board meeting. They thought it was set up for LA officials. The families in the inner London borough who had regularly attended their Board meetings, now questioned if they had achieved anything. Every family expressed concern for the future. All interviewees believed the higher support needs associated with PIMD, were constantly overlooked by LA planners. In particular they referred to the lack of, respite, physiotherapy, trained staff, planned transitions and

appropriate day services. One family, referred to a need for effective leadership. The families, who felt staff needed to be managed more effectively, echoed this sentiment.

5.9 Conclusion

This chapter sought to explore the ways family carers of people with PIMD, made sense of the big ideas of VP. The underlying philosophy, based on ideas of rights, independence, choice and inclusion drew short shrift from the families. They were more concerned with the real lived experience, as they saw it, the reality of life with and for an individual with PIMD. As this new way of working has been in place for over ten years, the philosophy underpinning the agenda, ought to be embedded in practice by now. Unfortunately, it appears from the responses, this occurs only in the most superficial way. This may be because, ultimately, a model based on self-empowerment and independence does not adequately accommodate lifelong dependency and lack of mental capacity to self-advocate.

The next chapter will look at the results of the focus group discussions with formal care workers at three day centres in inner and outer London.

Chapter 6 Care Workers

How knowledgeable are formal care workers of the VP approach? Is there any evidence of a theory-practice gap?

This chapter is the final piece of the triangulation at the heart of this thesis. Whilst the last chapter focused on the views of family (informal) carers the focus here will be on the views of paid (formal) care workers. These were obtained via focus group discussions, initially stimulated by the showing of a short film of an individual with profound intellectual and multiple disabilities (PIMD). The same set of questions, were used to guide the focus group discussions, as those posed to the family carers.

This chapter will discuss the manner in which the use of the filmed excerpts elicited deep and thoughtful discussion. Further, it will demonstrate the manner in which the film (and hence the film's subject) was able to disrupt the policy 'speak' of Valuing People (VP) and encourage workers to analyse their own attitudes and beliefs.

6.0 Sample centres / participants

The three day centres selected, cater predominately for people with PIMD. IL1 does not have adequate wheelchair access, which means they have fewer wheelchair users than IL2. However they both cater predominantly for people who would satisfy this study's requirements. The outer London (OL) day centre was purpose built and designed solely for people with PIMD. In order to strictly anonymize all participants' responses they will be referred to according to the Table* i.e. by centre rather than name.

See Appendix D: p265

6.1 Boroughs

At the time of writing the outer London borough was Conservative controlled whilst the inner London borough was run by New Labour. Due to the very particular nature of this study, it has not possible to include links to the local authority's websites as this could compromise the assurance of confidentiality, which was an important feature of the agreement to participate.

The inner London (IL) borough spends the bulk of the Learning Disability Budget (LDB) on out of borough placements, especially for people whose behaviours are described as '*challenging existing services'* (Becker, 2006 p12). The VP aim of placing people in borough is therefore not fulfilled here.

The outer London borough has people living in residential care in borough, although their published commissioning strategy also highlights ongoing difficulties with finding suitable local accommodation for those with the more complex support needs. According to the manager, the majority of people attending the outer London (OL) day centre come from local residential care settings. It is not clear if it was pressure from these providers, which prompted the commissioning of the new service, two years after the local day centres had been closed. The manager believed this had been in line with the new VP approach. She also pointed out that the service had been specifically set up to cater for twenty-two individuals in 2004. However, at the time of interview (2011) the service was catering for in excess of one hundred individuals. Family carers also pointed out there is no other specialist day centre provision for people with PIMD in the borough. Newer service users are therefore being directed to outsourced generic agency provision. At the time of writing day service provision in the inner London borough was also under review.

6.2 Focus group discussion questions

As previously discussed the initial CDA of the VP policy informed the schedule of questions. These were all directly related to promises / objectives within the original document. The questions were used to guide and to bring focus to the discussion. They were loosely set, with a number of prompts (see appendix B: p241). These prompts were useful for opening out the discussions, especially when participants were only providing monosyllabic responses.

6.3 Focus groups

The focus group discussions were conducted at the three aforementioned day centre sites. Two meetings were conducted at each site, within three months of each other between August 2010 and October 2010. On each occasion the participants were handed an Information/Participation sheet as they arrived. They were advised to sign the attendance

sheet. The researcher elaborated on the aims of the research study as people settled. Each meeting lasted approximately 90 minutes.

The workers at all sites were predominantly new to post, ranging from weeks to an average of 2-3 years. This meant few had been in post pre VP (i.e. before 2001). However, at least one worker in each of the three sites, had experience of re-settling people with ID from long stay institutions, into community settings during the 1980's and had been working in day services ever since.

One of the aims of this study was to generate on the ground responses to the VP agenda, by workers in the field. The focus groups therefore presented an opportunity for interaction, which further stimulated the discussion. This gave individuals an opportunity to express their own feelings and expand on experiences, which in turn led to insightful emerging ideas.

The researcher employed a constant probing style to peel back the layers, as it were, of each individual's understanding of various concepts. In this way, the discussions elicited vital information about workers' understanding of said concepts. This was where the groups came to the fore. The study required deeper responses than a yes/no questionnaire might reveal and as the discussions progressed participants warmed to the subject. Policy makers rarely consult care workers, which is possibly why the exchanges were so rich in honest and open exchange and the workers welcomed the opportunity to be listened to.

The use of focus groups also revealed some fundamental differences, especially the lack of knowledge about basic terminologies. At one centre (IL2) staff expressed very superficial knowledge about ID in general and VP directives in particular. This was most apparent when individuals answered questions with jargonesque replies. On further probing it was clear respondents did not have a real understanding of the concepts they discussed. This gave an opportunity for the researcher to clarify various terminologies, which in turn led to further, more fruitful discussion.

There was a concern raised by all groups that the issues concerning people with PIMD are very specific, yet policymakers seem unaware of this. This echoed the sentiments of the family carers, as seen in the previous chapter.

Overall the groups were a valuable tool for accumulating on the ground insight into whether or not VP has achieved its aims and for reflecting on where practice might have improved or not, since its publication. The discussions were held at each centre in the slot usually ascribed

to training. In this way workers were not being asked to proffer their own time and service users were not deprived of any sessions.

The staff at the outer London centre arrived and settled quickly. They gave the impression that training sessions were a regular feature of their job. Having a specific room set aside for this probably helped. In contrast the room set aside for staff training at the inner London centre (IL2) was clearly unused. When the researcher attempted to set up in there, staff advised her, they didn't like the room because it was too stuffy. The researcher opened the windows and staff then complained the room was too small for meetings. The sense was that staff usually finished early on the allotted training day and that the planned focus group was an imposition.

The researcher eventually set up a TV in the dining area, with seats positioned round a table, so everyone had a good view for the film. After the viewing, it was quite difficult to draw any responses longer than yes or no from the participants. However, on the second visit they were more forthcoming from the outset.

The staff at IL1 appeared slightly harried and distracted. On the first occasion the researcher arrived as service users were leaving. This was managed in relays, especially as staff could only exit one wheelchair user at a time. As they moved out of the communal area, into the reception area, another staff member was spraying every surface with cleaner. (This included the vinyl couches and the chairs we were all about to sit on.) It occurred to the researcher that this could be seen as a psychological mechanism for containing unconscious anxieties (see for e.g. Jodelet, 1991). Once all the service users had been boarded onto their transport, the staff assembled back in the communal area to watch the film. As with IL2 there was no specific room for staff training.

6.4 Filmed excerpts

The participants appeared to watch the film in deep concentration. There was no talking or shuffling for example. When it finished and people were asked for their initial reactions there was little response. Interestingly at all centres, when the researcher took the lead and queried if people would describe the individual as independent, for example, they all replied emphatically 'no'. This then opened out the discussion.

IL2 possibly took the most prompting and oftentimes their answers were a basic yes or no. On the other hand the OL staff gave more cogent answers and there was some interaction between the participants. For example, one woman explained she came from Slovakia and it was common practice there, for parents to place their children with disabilities in residential care. This prompted another member of staff who came from Africa, to opine the same thing was common there. Another person joined in by saying she thought it was a Jamaican thing.

The most interaction between the participants occurred at IL1. They presented the most emergent style of thinking throughout their discussion (See, for e.g. 6.6.1, pp 161-168). As previously stated, the use of the filmed excerpts was also an attempt to include an individual with PIMD in the research design, in as meaningful a manner as possible. There has been some discussion about the difficulties of enacting notions of participation, decision-making and consultation with the target population (Concannon, 2005, Redley, 2009). However recent research, which has attempted to portray these notions, within the current social model approach, has fallen short of its aims (e.g. Whait, 2011). For this reason the thesis was attempting to establish a methodology for including people with PIMD in their own research, from a critical realist perspective. This allows us to '*bring the biological body impaired or otherwise, back in'* (Williams, 1999 p797). It is a contention of this thesis that over ascribing mental capacity to an individual with ID is as oppressive as under ascribing.

6.5 Analysis

The discussions were recorded verbatim, with a recorder and boundary microphone. Reflective notes were also made as soon as possible after each session. These notes were an invaluable aid as the research process progressed. For example the researcher reflected on her style of facilitation including the use of probing questions. As the sessions progressed she became more confident with allowing the silences that sometimes ensued, rather than jumping in with another question. People responded to this thinking time and discussion would then flow between the participants. This was the aim, rather than people simply responding to questions with a yes or no answer. One of the main concerns that became apparent at the transcription stage was the difficulty in identifying individual speakers. Also at times, especially when more than one person spoke, it was difficult to make sense of what

was being said. Notwithstanding the use of a transcription machine meant it was possible to stop and start the recording as many times as necessary in order to clarify statements.

As it was not possible to identify individual speakers, the quotes are authored SM (staff member). Sixty-seven (67) pages of transcript were analysed in a similar fashion to the family carers' data (see C5 p130).

The researcher worked through the data using the guiding principles of data reduction, display and verification (Miles and Huberman, 1994). Devising the initial research questions and conceptual approach (the '*anticipatory data reduction*') occurred before the data collection (p10). At this stage the research question was adjusted to one specifically seeking evidence of care workers' comprehension of the VP approach, rather than the initial query, which asked 'how workers reconciled their own understandings of PIMD with the new VP approach'.

The later examination of transcripts was therefore conducted with this in mind. Throughout the transcribing the researcher included notes where there was a cross–reference, contradiction or similarity of description with the family carer transcripts or with the VP analysis. For example underneath an exchange with workers describing new approaches to issues of communication, which ended with them explaining, '*no we haven't started the training yet*', the researcher notes, ' NB is this an example of the 'going to' services described by a parent?' The long exchanges were then ascribed specific headings. Hence, underneath a two- page exchange between workers, the researcher notes 'all of this could be in Choice'.

A colour coding system was utilized at this data reduction stage, in order to assign various responses to a general subject area. These areas were in turn gradually summarized into five emerging thematic headings.

6.6 Emergent themes

The aim of the film was to demonstrate the four key principles of VP, i.e. rights, independence, choice and inclusion (DH, 2001 p2). It was anticipated that tangible examples would be more effective at encouraging discussion than simply stating abstract ideas. The film engendered lively debate, especially regarding the concept of independence, which no

worker at any of the three centres believed could be used to describe the woman in the film. Rather, at one centre (IL1) the staff constructed a discursive formation, which could be described as reasons for not accessing the community or reasons for not going out to a public place, based on the care workers' perception of the filmed individual as distressed by her surroundings. Other common responses were,

'we couldn't do that here' (OL), *'we don't have the time for that' (IL2),* or ' *that's a health and safety issue* ' (IL1).

The filmed activities being responding to were the woman carrying a plate from her living room to kitchen and later a cup. This was followed, by her being guided to flick a switch on the kettle. It took her a while to do all of these tasks, and since it was filmed in real time, it did seem long, although in reality only took minutes. This raises questions about the possibility for a truly person centred service. The staff at IL2 were keen to stress the fact that,

'we put the service user at the centre of the service' (IL2).

And yet they could not accommodate supporting an individual to carry her plate from table to kitchen. This chimed with comments from family carers in the previous chapter.

The participants referred to the film clips frequently as they grappled with questions they oftentimes found difficult. Their depth of understanding of VP concepts varied from centre to centre and this was reflected in the worker's responses. Ultimately their reactions to the filmed excerpts were at odds with the VP discourse of independence, choice and inclusion although they were also, often illuminating.

For instance the first theme describes the manner in which participants attempted to unpick ideas of levels of choice-making ability. This is why it is described as 'Choice or preference' (6.6.1).

There was much discussion about ideas of community and also lack of community services and negative public reactions, which made better sense to present as two distinct themes, 'Accessing the community' and 'What community?' (6.6.2, 6.6.3)

The theme of 'Care workers comprehension of VP definitions e.g. Learning disability/difficulty, Independence and Complex needs', demonstrated the difficulties worker's may have in keeping abreast of newer terms, for which they may not have a clear comprehension (6.6.4)

The film was a useful trigger to refocus participants to responding in terms of SUs with PIMD. This also illustrated some of the worker's superficial knowledge which underpinned the theme 'Big ideas embedded superficially' e.g. 'We keep all their choices in the ISP', 'Confusion about rights and independence' and 'SUs can choose not to go out. So if they want they can stay behind' (6.6.5).

The final theme of 'Policymakers lack of understanding leading to uniformed planning' echoed many of the families concerns raised in Chapter 5.

6.6.1 Choice or preference

As with the family carer interviews this was the most discussed theme. It also demonstrated a wide range of comprehension amongst the care workers with regard to the people they supported. There was a marked difference in responses, with regard to the concept of choice. Two of the centres' responses could be summed up as considered (IL1) and pragmatic (OL). The participants at these centres were thoughtful and open to the researcher probing for more than surface answers when they responded to the particular question about offering choice of care and support (See Appendix B: Q2 p259). However the IL2 staff were very focused on the idea of offering choice as an end in itself. They claimed to offer choice around, food, drink, workers and outings via verbal queries, picture exchange systems (PECS) and Objects of Reference (OR). They were keen to point out this was a feature of their service.

'*From the time of the placement the key worker will work with the service user (SU) to see their choice is represented in the plan. All their choices are listed in the plan*' (IL2).

However, when pressed for examples of SU's with PIMD making choices, the answers were not forthcoming. The researcher felt the need to use somewhat leading questions in order to gain insight into the worker's own understandings of the concept of choice as they described it. In the following exchange it is assumed SU's are choosing one particular worker, 'B', to feed them.

Researcher: '*How would an individual make a choice over who provides their support?*'

SM (staff member) '*Well you know a lot of them want B to feed them. They express that choice, because they don't let no other worker feed them*' (IL2).

A number of workers all murmur in agreement here. Another worker picked up the theme,

SM '*like take meal times. If this was an institution they would have set meal times. They have no choice, they have to eat then. But, if someone doesn't want to eat right now, or like D who likes to eat his meal on the couch, we let him. That's choice*' (IL2).

Researcher '*So you can work out if a SU has withdrawn to the couch and refuses his lunch, that is because he has made a choice not to eat right now*?

SM '*yes.*'

Researcher '*I'm just wondering, is refusal a choice or withdrawal from making a choice*?

SM '*It's still a choice innit? You have the choice, yes or no*' (IL2).

Researcher: '*And what about the SU's who cannot communicate 'yes' or 'no'?*'

SM '*We just meet the SU's needs, when they make their choice, we make sure we offer them their choice*' (IL2).

In the above exchange, the workers appear to understand choice as accepting or rejecting. When they spoke about SU's refusing to let certain workers feed them, this was also seen within the context of accept or reject. However, as the discussion progressed, the workers described how SU's were offered a choice of meals. When pressed, it transpired that the choice was offered the day before and

SM ' *well, yes, it's those who are able to choose their meal obviously*' (IL2).

This day centre caters predominantly for people with PIMD, although they do have some SU's who are more able. Throughout the discussion the researcher was constantly tying to draw SM's focus back to those with PIMD.

Researcher '*I was a bit confused there about how H, for example would chose her meal for tomorrow.*'

SM '*Well, we can use pictures too for those who can't speak.*'

Researcher '*you have pictures of all the meals?*'

SM '*No, I meant going out, like going to the park or going swimming, we can show them pictures to see if they want to go*' (IL2).

This confusion around the concept of choice was even more apparent in an exchange regarding the filmed portrayal of accessing the community.

SM '*she don't look happy you know'*.

Researcher *'does anyone else thinks that?'*

SM ' *she's self injuring* '

SM '*yeah and she's verbalizing it ……. '*

SM ' *there's too much going on around her and she don't like that'*.

These workers were concerned the individual was experiencing discomfort. They noted she was making a noise and tapping her nose quite vigorously. The researcher explained that her vocalizations were a reassuring hum and whilst the face tapping is a sign of anxiety, it is more a feature of her sensory integration issues than a response to her environment. The fact that people had responded as they did to the film, created an opportunity for the researcher to expand on this.

SM '*Oh you mean like R. He always bangs his head on the wall. I used to worry about it, but then they told me it was stimulating him. So now I know that's his choice.'*

Researcher '*What do other people think, in light of what we saw in the film, regarding someone's capacity to make a choice.'*

SM '*it's not, well …. Now I'm getting confused.'*

Researcher *'Well there are a few things. Firstly, people who engage in sensory based, self stimulatory behaviours, usually do so because of their early developmental level.'*

SM '*someone came in once and said most of our service users are at such an early developmental stage, they can't be measured.'*

Researcher, '*There you go. So, if that's the case, do you really think they're making a conscious choice to do it?'*

SM '*probably not then.'*

Researcher ' *who here has heard the expression, 'informed choice?*

No response.

Researcher *No? I think it's a good way of understanding. We talked a lot about choice and preferences, but it takes quite a bit of mental capacity to make an informed choice. Do you really think R thinks through and makes a decision to bang his head on the wall?'*

SM *'er'* …..

Researcher *'I agree he gets some sort of sensory feedback from doing it, I just don't think anyone would mean it's OK for him to do it.'*

Another SM *'See we don't know it, but for some of the service users, they feel things differently to you or I.'*

This exchange with staff at IL2, contrasts with the staff at the outer London (OL) centre who answered a question about how people could exercise choice thus,

SM 'e*ven though we interpret, it is still an assumption. We presume what we think they are communicating. We don't know for sure'* (OL).

The staff at this centre demonstrated clear comprehension of their SU's levels of mental capacity and the impact of this was constantly monitored.

SM *'Someone may appear to be making a choice, but that is not always the case. Sometimes people will note that someone doesn't like a particular food or drink, but that may only have been that day. It's not forever. Sometimes it's hard to know, this is why we have the feedback sheets'* (OL).

This was the only centre using feedback sheets throughout the day in a variety of settings. The staff referred to the use of these during the discussion, which corroborated the manager's earlier comments when showing the researcher around the unit on the initial visit.

Researcher *'So you keep all these records and then adjust things according to how people have reacted?'*

SM *'That's right. They have a range of depth, so we record things like eye contact, or if they tense or resist' (OL).*

SM *'There are many, many charts and forms for each client. Their individual progress is monitored, as are all interventions. As this client group cannot self report, the staff are*

developed along Intensive Interaction* lines, in order to develop an acute attunement to their client's responses' (OL).

(*For further information see, http://www.phoebecaldwell.co.uk/ork/html)

With regard to choice of worker, the staff used their observational skills to surmise preferences, if any.

SM *'Someone will smile lots more, or you can tell from their body language they are more responsive'* (OL).

SM '*We would certainly pick a key worker to partner someone if they show signs of getting on with them '*(OL).

Staff at this centre, were clear about the mental capacity of their client group. They acknowledged, for this reason, their work is dependent on assumption, observation, interpretation and constant monitoring. These words kept occurring throughout the discussion. In contrast the staff at IL1, started out by explaining,

SM '*we have to offer them choice, innit*?' (IL1)

However by referring back to the film and asking if they believed the woman depicted was making choices, they expanded.

SM '*We offer them choice, but their development doesn't enable them to make clear cut choices. Like do they really understand we are offering them a choice*? (IL1)

There then ensued a lively and thoughtful analysis of how choice was offered and interpreted within their service.

SM '*I mean, when we offer them say bowling or swimming, do they really know what we mean?'*(IL1)

For example a number of workers believed SU's 'acted out' if their rota was changed, because they were not '*getting their choice*.' However, another worker pointed out,

SM ' *that's because it's their routine, if that gets changed, how do you get that across and how do we offer them another choice*?' (IL1) '*It's not so much the choice, but when the activity is not there, they are aware of it*' (IL1).

As with IL2, this particular day centre does have some clients who are more able to express their views. The workers would include these particular individuals to illustrate the discussion but had to be reminded that the researcher was only trying to understand the approaches they used with the clients who had PIMD. Here, as with IL2 there appeared to be managerial directives that compelled the staff to offer choices. They reported this was the first time they had really thought through, what this actually meant for their client group.

SM '*I personally think because we continue to do this, we just become like .... We just do it. Now you is asking questions, that we don't normally think about* '(IL1).

As the discussion moved on to the choice of meals, the staff began using the word prefer much more. As in,

SM '*she prefers the consistency of mashed not liquidized food*' (IL1).

Or,

SM '*she prefers water, but Speech and Language (therapists) say she has to have juice with thickener*' (IL1).

At this point one of the workers queried, '*but is choice the same as preference?*' (IL1)

Here the researcher explained a little about mental capacity and levels of choice making, by referring back to the film again.

Researcher '*If you remember, the worker said to her, 'do you want to take the lid off '.... Or something..... who can remember?*'

SM '*And she just hand over her stick .*'

Researcher '*So in other words, if somebody does not understand that level of choice ... do you want to do this or that ....*'

At this point another worker posited that what they really provided were,

SM '*Options, they are options with a choice. We decide what the choice is ... so is that really a choice? If you say you can go swimming or bowling, but there's a mass of other things out there to do*' (IL1).

One of the aims of VP is for people to have more control over their lives. Hence the researcher, probed a little deeper.

Researcher '*Since having choice is meant to lead to more control, can you think of any people here who have benefited? For example whose behaviour might indicate they were less distressed or more engaged since being offered these choices?*'

SM '*Well, we could say A. From we start to give her more choice in what she do, although we can't do it everyday, we try to accommodate her*' (IL1).

SM '*Cos over the years her behaviour has got worse and worse, so the Behaviour Support Team (BST) suggested this choice*' (IL1).

SM '*but has it changed her behaviour?*'(IL1)

Researcher ' *What kinds of choices is she getting?*'

SM '*hers are complete choice, like what do you want to do today?*'

Researcher '*again, think of the film. I would suggest responding to an open ended option is beyond her mental capacity.*'

SM '*the BST also suggested she always have 1:1 support to limit her behaviour from getting unsettled.*'

SM '*the lady here is asking have you seen any change in the behaviour due to the choices she is now getting.*'

SM '*I think it's the 1:1 which is changing her behaviour not the specifics of choice*' (IL1).

As can be seen in the above exchanges, the workers at this centre were possibly not as informed as the OL workers. However, they demonstrated emergent thinking more so than the other groups. The choices they offered were to do with food preparation. As with the OL centre, this included an idea of observed preferences. The choice of outing (bowling or swimming) was claimed to be offered, but as with IL2 it was unclear how or indeed if, service users understood this. One service user was offered open ended choices, which staff agreed were unlikely to be meaningful.

6.6.2 Accessing the community

As previously mentioned, one of the filmed excerpts depicted the individual accessing her local community. She has a regular routine, whereby the same worker takes her each week to the foyer of The National Theatre on London's Southbank. There are regular free musical recitals, which she mostly enjoys. The fact that they are free and in an open public space means people are less likely to complain (as they have done at paid performances) if she does vocalize. She meets another support worker there, who enacts the same routine with her each week. This particular week she filmed the woman, once she had settled in and was listening to the music.

When this film was shown to the day centre staff, the responses were mostly directed to the woman's body language and vocalizations. Most of the staff were concerned she appeared distressed. The staff at IL1 were, especially concerned by her face tapping. They thought it looked very sore and uncomfortable and were concerned she was self harming. They thought the surroundings were too noisy for her. They were concerned she appeared overwhelmed by the sounds of the music and of people talking.

The staff at OL did not refer to her face tapping, however they did point out this was not an activity they could offer.

SM '*Mainly due to staffing, it's obvious she need's 1:1 attention and we couldn't provide that*.'

The researcher reassured staff that whilst the individual may experience distress at times, the filmed excerpts shown, depicted her in a relatively relaxed and calm mode.

The discussion was then directed to what people understood by the term accessing the community and what relevance this bore for their own service users. This then led into a much longer discussion about the general public and their negative attitudes to people with ID.

The following exchange took place at IL2. Looking back at the reflective notes made immediately after this session, the researcher observed that staff were not as responsive as those at the other centres. She worried they felt they were being tested. When they did contribute, it felt as if they were repeating statements they had possibly heard in a training session, rather than their own thoughts.

Researcher '*VP talks about 'new opportunities as part of the local community'. What do you think they mean*?'

SM   No response, blank looks.

Researcher '*It talks a lot about people 'accessing the local community'; what does that mean?*

SM   still no response.

Researcher '*OK, let's just think about the word 'community', what does that mean?*

SM '*anywhere outside this practice'.*

Researcher '*what do other people think?'*

SM ' *Yeah, away from here'.*

Researcher '*so you don't feel this centre is a part of the local community?'*

SM '*this is an institution.'*

Researcher: '*I'm wondering if you think back to the film we saw, did it suggest an idea of inclusion*?

SM   no response.

Researcher '*OK, perhaps we could talk about what inclusion means?*

SM '*It means being included, included in the community'.*

SM '*you see, the new opportunities we have, are accessing the community. We just use the centre as a base these days.'*

One member of staff tried unsuccessfully to expand the discussion.

SM   '*I don't see that they are new. It's just the new idea, that instead of staying all day at the centre, people can access the community.'*

There was no response to this so the researcher tried to move the discussion in another direction.

Researcher '*I get the impression that for some of your SU's, coming here, then*

going out again, coming back, then maybe out again in the afternoon, that could be quite confusing for them?'

SM '*It gets confusing for us sometimes*' (everybody laughs).

In the above exchange, the community is simply the world outside the day centre. The opportunities are any activity that takes the service users out of the centre. The centre appears to have negative connotations by being described as an institution. Or indeed, '*just a base.*'

In contrast the OL day centre staff state unequivocally, that they recognize their clients,

SM '*don't recognize what we are doing, but they know if they like pleasant sensory experiences, so we concentrate on that type of approach, rather than some idea of accessing the community which is meaningless for this group.*'

Another worker joined in,

SM '*why would they want to be dragged around the High street or into MacDonalds? They need therapeutic interventions and support and that is what we believe is the best thing for them.*'

The OL centre was purpose built for people with PIMD. The staff explained that all local day centres were closed down around the time Valuing People (DH, 2001) was published. However a few years later the LA recognized there were a core of people who needed the specialist support, a centre could provide.

SM '*We were specifically designed as a service for 22 people and yet now four years later, we have roughly double that each day. There is an increasing population of people with HSN. Peg feeding has led to greater life expectancy as well and we seem to have many Rhetts clients.*'

IL2 was also purpose built. It has a gym, a soft play room, a sensory room, specialist music making technology called Soundbeam, various individual training rooms, staff rooms, offices, a communal room, a dining room and kitchen. There is a reasonable sized garden to the rear, with access onto a communal park. All of these areas are underused now, since the community activities commenced. Whilst most of the workers were keen to describe the new range of community activities on offer, the worker who had questioned if it was the

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opportunities, which were new or simply the idea of leaving the centre to access them, tried again to further the discussion.

SM '*We go swimming, bowling, to the park, hydrotherapy, sports, library, cycling, parks.*'

SM '*we're lucky we have so many places people can go to, all in walking distance.*

Researcher ' *I thought you said the hydrotherapy was in Peckham?*

SM '*yes, I meant parks.*'

SM '*I know you said that and spoke about choice, but how many times can our SU's go to the same park? Not being funny I know that place like the back of my hand now. What must K think? 'Here again'.*'

SM '*Because she's not going to develop that much, K can only give you a look so how do we know if she's enjoying it?*'

This led to discussion, about who actually accesses the range of activities and how often they are offered. It was unclear if the stated range of activities was already on offer or planned for some future stage. Each time the researcher attempted to clarify this the response was vague.

SM '*Yes, they say they are having the cycling in B Park this year.*'

Or a query about the library was answered with,

SM '*yes it's supposed to be opening at the end of the year.*'

Neither was it clear if the range of activities, were being accessed by people with PIMD. For example when one worker explained

SM ' *we had a beautiful excursion today we took a group to the secret garden. P was giving us a running commentary* '

Researcher *so how do people get to access all the different activities?*"

SM '*well, it depends on the day and the numbers*'.

The researcher tried to draw staff on how they deal with those who may indicate they are not happy to go out.

SM '*oh well that's their choice, if they don't want to they stay here.*'

Again, it was difficult to ascertain how staffing levels worked, if people apparently chose to remain in the centre at the last minute.

The impression was of, well intentioned but not well informed staff. They were not clear about the range of activities supposedly on offer. These appeared to be delivered on an ad hoc basis. Also it appeared staff were asking people who lacked the capacity to understand their questions, what they wanted to do. This must end up being very frustrating for service users and staff alike.

Trying another tack, the researcher asked about some of the drawbacks to community activities. None of the workers at this centre enjoyed having to use public transport.

SM '*Being forced to use public transport.*'

SM '*Sometimes we have five or six big wheelchairs, it can take a while just to get on the bus.*'

SM '*Yeah it can take a while and we do hold the other passengers up.*'

SM '*and some of our people have severe epilepsy, physical disabilities and behavioural problems. It's not easy getting them all on a bus.*'

The community outings at IL1 appeared to be less formal than those at IL2. Because their building is situated within walking distance of the local town centre, they often accompany groups of SU's walking there or to the adjacent park. They described one of their regular longer outings, which take place once a week. This is to a café in a supermarket on the other side of the borough.

SM '*We don't know what day, it depends if transport is available*'.

This lack of awareness by local authority planners, (in this case the transport section) of this client group's needs is further discussed in section 6.8.

6. 6. 3 What community?

The discussion of community at IL1, started off by focusing on notions of being accepted. The staff were keen to point out that

SM '*it's where you live, in society.*' '*Being accepted.*' '*Walking around and working in a place where you are accepted. You see people daily, they are accepting you without saying 'I accept you.*'

However, very quickly it transpired that the staff had real concerns about how little their SU's were accepted.

Researcher '*Do you think ……..*'

SM '*No, the answer's no, but carry on.*'

Researcher '*No?*'

SM '*You're gonna ask, do you think they're included?*'

Researcher '*Please tell me.*'

SM '*Inclusion as in we try and access it, the community, but whether it's accepting? If you mean are they accepted? We try and ....*'

Researcher '*So people aren't accepting*?'

SM '*Not in our lifetime.*'

At this point the researcher referred back to the filmed outing to The National Theatre. She explained the same worker had been doing the same excursion for some years. The general public were not always accommodating. For example they often had to wait for the disabled toilet because an able person was using it. There was a rush of responses at this stage; it is clear this is quite a raw subject and staff had not had the opportunity to discuss it at any length. They discussed indirect discrimination and outright negative attitudes.

SM: ' *A key word I would use associated with people with LD in the community, is tolerate. It's not whether they're accepted it's about being tolerated. A business or whatever will tolerate in that they allow people in, but are they accepting*?

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SM: *'Yeah, people seem to find ways to not accept … more subtle ways like the hours they are open or not.'*

SM: *'there's a lot of ignorance out there.'*

SM: *'They don't want to socialize; they think it might be catching. Like if you sit near them they will get up and walk away.'*

SM: *'We get this all the time, like if we go to the park, they walk away from us, if we go to a cafe they get up and walk out.'*

Their sentiments chime with comments from the discussion at IL2

SM: *'It's a pity they didn't tell the community we were coming. People's ideas*

can't change overnight.'

Researcher: *'It's been ten years now.'*

SM: *'Even so, people have their ideas don't they? It just feels sometimes, like …*

Well, our people need changing places, where are they? It feels sometimes like we're going through the motions, but why?

There was further discussion here, about whether the negative attitudes were particular to this inner London borough. There is a high percentage of African /Caribbean people and staff at both of the day centres brought up the fact that in their culture, people with ID are institutionalized. Even more so, as one worker pointed out,

'You can grow up in a large family and you don't even know you have an older brother in an institution. It is never talked about. You might only find out about it when they tell you he died' (IL1).

Interestingly when the OL participants had a discussion about these cultural attitudes, they realized the attitudes were not confined to African/Caribbean.

SM ' *it's different in my country. In Nigeria everyone is in, you know, homes'* (OL).

SM' *but you know, where I come from, in former Czechoslovakia, it was a common practice to take all babies with Down Syndrome into care at birth, until 1989* (OL).

The idea was later posited by one of the IL1 participants, that the problem could have nothing to do with cultural attitudes. This worker pointed out that the local area is very crowded and busy.

SM '*People aren't all bad they are just caught up in their lives. We were talking about this the other day. They were asked to leave a café, because the person they were supporting was kicking off, they were causing a commotion, so in that case you have to leave. Yes, people need to accept disabled people, but if we are in a big group, we can be intimidating to the public too*' (IL1).

6.6.4 Care workers' understanding of VP definitions, e.g. learning disability/difficulty, independence, complex needs

Learning disability/difficulty

OL staff were clear about definitions.

SM '*We understand that for people with a learning disability, the brain and the mind stops developing. So for example someone may have a mental age of two or even two months.*'

They also recognized the changing terms, which they (like most participants) attributed to ideas of political correctness.

SM '*Because of PC, sometimes people are hesitant to describe someone, because they are not sure if it is the right term. Learning disability or difficulty? They used to say sub normal and mental handicap, but now it's unclear who people are referring to.*'

SM '*No one really knows. The general public are often concerned that they have said the wrong word, so they end up not saying anything for fear of offending.*'

When the staff at IL1, were asked what they understood about severe learning disability, the researcher was corrected and told '*severe learning difficulty*'.

Researcher *'Can I ask why difficulty and not disability*?'

SM '*Because disability is a disabling term, difficulty is friendlier.*'

Researcher '*Does anyone else think that*?'

SM It's *just the way it is, innit? After a while one term gets out of fashion. Disability is out of fashion now, so we have to say difficulty.*'

The staff appeared to understand the new term as somehow less threatening than the older disabling term. It could also have been a reference to the local self-advocacy group for adults with ID, which is called The Friendly Group.

In the ensuing exchange, the researcher attempted to tease apart, staff members' understanding of the various terms used within VP. They had an understanding that people with SLD,

SM '*don't have physical disability as well; they can do more for themselves, like travel on public transport.*'

However, the term complex, which VP uses to describe additional specialist health care needs, including autistic spectrum disorders (ASD), was seen as an umbrella term for all people with ID.

SM '*I've said this before, I believe all people with LD have complex support needs.*'

Note: It was only on transcription that the researcher realized the same worker who had the exchange about the terms difficulty/disability with regard to ID, had apparently not applied the same reasoning with regard to physical impairment. This suggests the idea of 'friendliness' was tied in to the description of ID in particular. Did the worker feel she was being friendlier describing someone as having difficulties rather than as being disabled? If so, why?

Staff at IL2 also corrected themselves over the term,

SM *' people with learning disabilities, I mean, er difficulties, this is a different idea, we've been to so many trainings. We're not supposed to use that word anymore cos it's being phased out.'*

SM *'We are changing our practice, you see. SU's can have a better life now, than you or I'.*

However when they were asked directly what a learning disability was, the responses were less clear.

Researcher '*Who can tell me what a LD is*?

SM *'It means he knows how to wind me up.'*

Researcher '*I think I know who you mean. Do you really think he does that to deliberately wind you up?'*

SM '*He knows what he's doing.'*

Researcher '*And how can you tell*?'

SM '*Cos of that look he give me, like he's saying 'Ha, Gotcha'*

Researcher '*VP discusses complex needs, what do you think that means*?

SM *' well if you think about it, having a learning disability makes everything else difficult, so it's a kind of knock on effect.'*

SM '*because you have to talk slowly, so someone can understand you.'*

Researcher '*Do you think most of the SU's here understand you*?'

SM '*Oh yes, they certainly do.'*

SM *'You'd be surprised how much this lot know.'*

Researcher '*Even those we call PMLD*?

SM *'Of course.'*

These were the same workers who talked about changes in body temperature being an indication of whether or not someone wanted to do a particular activity.

Independence

OL participants did not interpret the islets of independence approach of the film, although they did reveal this in their own practice.

SM: *'We recognize that the overwhelming majority of our SU's, well actually all of them, they will always have very high support needs, because of the nature of their disabilities. There's no getting around that. But, that's not to say that we can't encourage them to use a spoon rather than be fed all the time. If they can learn to half feed themselves, that's a major achievement and should be celebrated.'*

When the discussion at IL2 was focused on ideas of independence and dependence the responses were more thoughtful than the discussion of choice. Staff had viewed the filmed excerpts, which captured perceived islets of independence. In this case, carrying a cup from lounge to kitchen, assisted by vocal prompts and audio cues. No one thought this could be described as independence, islets or otherwise.

Researcher *'Why not*?*'*

SM *'Cos she cannot do any of these things on her own. She has to have some kind of support in everything she do. See, she is following the sounds the SW makes. If the SW didn't do that, the tapping and verbally encourage, she wouldn't do it.'*

Researcher *'VP says*, by independence we do not mean doing everything unaided. *Couldn't this be an example of that idea?'*

SM *'No, no, no, you just getting into twisting or playing with words. She do it or she don't. If you can teach she, and after you use the sounds for a while, then she do it on her own; that's independence.'*

SM *'Even without the sounds, she has to use her stick. That helps too.'*

These workers went on to compare the woman in the film with certain service users at their centre. They described their differing support needs by referring to an individual who could manage quite a bit of his dressing, but needed help doing up his shoelaces.

SM '*That's what they mean, that's what did you say, 'not all unaided'. But G can walk around on his own, can't he? He knows what he want.*'

Another worker compared the woman in the film to someone with physical disabilities who was dependent on someone pushing their wheelchair for them.

SM '*I'd say it's the same for this woman, because she has to have someone guiding her, directing her. She's not like, you know you see blind people with a cane and they, or they have a guide dog, but they can travel on their own. Now you could say they are independent with support like. The support of the cane or the dog. But this woman cannot do that, she is dependent as much as H or E, because she can never do it on her own.*'

Complex needs

NB: There were no SU's with ASD at the OL centre, since the LA had opened a separate Specialist Support Unit in 2005.

Queries at IL2, regarding any improvement in specialist services, particularly for SU's with behavioural support needs which challenge existing services (described as challenging behaviour, within VP) drew little response. No one knew the formal definition for challenging behaviour (CB), which has been in use for some time.

'*Severely challenging behaviour refers to culturally abnormal behaviour (s) of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour that is likely to seriously limit use of, or result in the person being denied access to ordinary community facilities*' (Emerson, 1995 p44).

IL2 staff descriptions were focused on the individuals rather than the severity of the behaviour, or associated limited access to community facilities.

SM: '*it's when they scream and shout or head bang or something like that.*'

SM: '*it's behaviour that can be destructive or self injurious.*'

Queries regarding SU's with ASD also revealed little understanding of specific support needs.

Researcher '*What about your SU's with autism?*'

SM '*We don't have any with autism*'.

Researcher '*Oh, I saw D when I came in and I know M still comes here.*'

SM '*yeah, but they're not so severely autistic, its ....*'

SM '*We have quite a few but none so severe the autism. We have worked a lot with O when he first came, we did a lot. We now know it's no use trying to fight him.*'

Researcher '*You don't have a plan you follow, or ASD guidelines?*'

SM '*Nah, they're not, they don't need it.*'

Researcher '*So have you heard anything about this new Autism Strategy?*'

SM '*No.*'

SM '*Being honest, since the Autism Act I don't think anything's changed here.*'

SM '*I'm just thinking, with this new style of service, your SU's with autism might be having some difficulty adjusting?*'

SM '*I don't think so.*'

Researcher '*for example, how is M these days?*'

SM '*M is M, he's fine, you just have to know how to handle him, eh K?*'

Researcher '*What I'm trying to explain though, is that M may be confused by the unpredictability of this new style of service.*'

SM *'Well you know, as we said, any of the SU's can choose not to go out. So if they want they can stay behind.'*

This exchange demonstrates how poorly informed these staff are. The lack of understanding of basic ASD support needs is clearly contributing to the behavioural difficulties they are encountering with some of their service users. This corroborates what M's parent had said earlier (FG:I, pp 101, 105).

It cannot be a coincidence that the staff at IL2, who had the least knowledge of LD, ASD, CB, etc. presented the most confused approaches. For example, mixing levels of choice approaches, failing to acknowledge need for ASD support, repeating words or phrases superficially. They tended to contradict themselves, one minute saying everyone could choose then later when discussing how staff are assigned to SU's they pointed out,

SM '*well those who can't choose, we do try out different staff*' (IL2).

This is the larger of the two inner London centres and has the most SU's with PIMD. The other centre, IL1 has more SU's with SLD and none with ASD.

6.6.5 Big ideas embedded superficially

One of the main difficulties encountered in the discussions, was the manner in which staff, particularly at IL2, appeared to refer to SUs with PIMD. However, when asked for specific examples, it usually transpired they were referring to SUs with more capacity. In fact it was often unclear if they were referring to people who could make informed choices or not. And it was not always clear if workers knew the difference. They presented the most superficial understanding of the key terms and core themes of VP. They also appeared to have misunderstood or misinterpreted information from previous training sessions. This must have impacted negatively on their working practice.

'We keep all their choices in their ISP'

The discussion of choice as a concept has been referred to in section 6.6.1. However it seemed important to include evidence, which demonstrated the staff were struggling to understand and incorporate this concept into their working practice.

SM   'We keep all their choices in the ISP.'

SM   *'We also do consultations with SU's. We speak to them, the more coherent ones, we use pointy stickers and they stick on a piece of paper what they want.   They're involved, but only the more coherent ones.'*

Researcher: *'well, you know my interest is how do we manage this for those less coherent?'*

SM   *' We are doing a training course which will help us enable those with more severe needs to access communication skills.'*

Researcher *'I guess I'm now wondering, how do you access something ……'*

SM   *' We have the technology, there are software programmes too.'*

Researcher *'And you use these here, can you tell me some more about this?'*

SM   *'No we don't have it. We haven't started that training yet.'*

This exchange led into discussion of the changing practice. This seemed to be a mixture of person centred approaches and best interests decisions. There was some confusion with both ideas though. One worker stated that before a new client commenced

SM *'the home manager and the team leader come together with their PCP, where the services are at the centre, whatever they do at home, we keep here the consistency.'*

This prompted some further discussion about the way a later meeting might be called to assess and review their programme.

SM *'We all have to follow guidelines. If we want to do something differently we have a best interests meeting.'*

SM *'No no no, If you notice a SU likes this activity you don't call a whole meeting.'*

SM *' No no no, only when it's in the PCP.'*

The above exchange at IL2 demonstrates some quite muddled thinking. Staff appeared to be quoting from a training pamphlet.

SM ' *will help us enable those with more severe needs to access communication skills.*'

When pressed they referred to software programmes. Worryingly this echoes the views of the local People First organization who referred to the computer and software programme used by Stephen Hawking when the researcher had enquired.

It is worth comparing the exchange with the staff at the IL2 centre, with the following discussion of technology at the Ol centre. The software programmes, which can track eye movements, are at a very early stage of development and their use is being trialled by the S&LT team. Their use involves setting up a screen at eye level. The therapist moves a mouse over a particular image and the programme then records, whether or not the individual has followed the direction of the mouse. As they themselves point out,

SM ' t*his also depends on the person. You know, they have to be at a certain level where they know what they want to say …. So yes, someone with a very profound physical disability will be able to use it as a tool for communication. We are only at a trial stage here and we only use pictures. So, yes we can see that a SU is following the picture. But it's not a way of interpreting body language. We can't say, 'oh look, he moved his leg slightly, that means he wants a drink ' type of thing.*'

Confusion about rights and independence

There seemed some confusion amongst the workers, especially those at IL2, about responding to SU's. Some appeared to believe everything must be decided at a Best Interests meeting, whilst others believed they could make the call themselves. Veering the discussion towards ideas of SU's rights was also confusing.

A number of the workers talked about,

SM '*giving people rights, by offering them choice, or listen to them or if they show us something they want to do.*'

SM   ' *Yes, I give G his rights by accessing the community.*'

SM   '*you have the right to privacy, so we shut the door when he goes to the toilet.*'

Researcher '*And what about his personal care*?'

SM ' *well we encourage the SU to be independent, so they do it themselves.*'

Researcher ' *And what about those who cannot manage*?'

SM '*We change their nappy for them.*'

Researcher ' *I'm still trying to focus on the personal care for someone who can use a toilet, but not say, wipe themselves.*'

SM ' *No no they can do it, they can do that by themselves.*'

Researcher '*So everyone here is either incontinent and wears a pad, or they can*

manage the toilet themselves?'

SM ' *Yes.*'

These concepts have possibly been alluded to in some training session and are now somewhat superficially incorporated into the workers' narrative. This also applies to their understanding of independence. Unfortunately they seem to believe, this state results from encouragement. Their insistence that all their SU's either wear incontinence pads or manage their own personal care is contradicted by some of the previous family carer interviews (see p104).

'Service users can choose not to go out. So if they want they can stay behind'.

Community inclusion was described as one of the four key principles of VP. The staff at the IL2 centre spoke about excursions and outings as a feature of the new way of working. Unfortunately when pressed about how this new informal style suited their clients, a typical reply was,

SM '*well, you know, as we said, any of the SU's can choose not to go out. So if they want they can stay behind.*'

Researcher '*so would it be fair to say that this new style of service does not suit all your clients? For example the difficulties you have reported in accessing public transport and the lack of changing facilities. Also for others, the difficulty seems to be with the unpredictable nature of the outings.*'

SM '*But we have to do the outings and we have to make it the best for the most isn't it*?'

This contradicts what was originally stated about SU's having the choice to go on an outing or remain in the centre. They appear to be struggling to fulfil the VP requirement of a one size fits all approach, where everyone is deemed to be capable of independence, even with regard to their personal care. Surely this contravenes a human right to be treated with dignity?

Whilst IL2 staff struggled with their explanations, staff at IL1 supported each other in the discussion, in order to explore ideas more deeply. This was why the researcher described their style of thinking as emergent.

SM   *'You mean how do we give them independence?'*

SM   *' Or how do we support them to be more independent?'*

SM   *'You mean like what we done with T, to try and get her on her feet? Try*

and get her using the walker?'

SM   *'The trouble is now, there is no equal opportunities, everyone's gotta be treated in the same way. They don't seem to recognize everyone is different. That's why this one size fits all, don't make no sense.'*

SM   *'If you look round this table, everyone here is different, they all have*

different tastes, strengths, whatever …'

In the above exchange the first worker is gently directed by the second and the third comes up with a lovely example, of the kind of approach the OL staff use, to encourage islets or moments of independence. The latter exchange is an example of the Hegelian dialectic process, whereby the workers' comments portray the exact opposite of the core VP premis, namely the idea of equal opportunities. Her comments are a neat refutation of the one size fits all approach, so championed by this policy.

When the discussion turned to ways in which the policy was impacting on their service, the issue of Individual Service Plans (ISP) arose. The IL1 staff members were sceptical about completing them on behalf of SU's. Dreams, wishes and aspirations are all quite abstract notions. It is unclear how they could be anything but subjective assumptions. These would surely vary considerably depending on who was creating them. When queried about Person Centred Planning (PCP) another new approach mooted by VP, staff were unable to give concrete examples of this in their own working practice.

SM '*You mean the way we have to fill out their aspirations and dreams and*

 stuff on the ISP?

Researcher: *'How? You have to ...'*

SM *'We have to imagine what a SU's dreams and wishes are, based on what we know about them.'*

Researcher '*So, in that case it's not their aspirations, but your assumptions*?'

SM *' Exactly.'*

Researcher *' Who can explain PCP to me*?'

SM '*It's about putting the person in the centre of the planning.'*

Researcher *' Okay, so can you give me an example of this*?'

SM *'Not really,'* (lots of nervous laughter here.)

Unlike the two inner London centres, the OL day centre staff challenged VP ideas from the outset. When asked what they thought was meant by the VP idea that '*everyone should play their part',* 'they answered,

SM '*we believe our client group do play their part, but possibly not in the way he means. They teach people about humility, about disability in general, just their presence raises awareness.*

SM *'That's why we take them to the Partnership Board and the Learning Disability Parliament.'*

They were the only group who offered clear descriptions and a basic understanding of the implications of having a profound learning disability. They were keen to point out that their SU's did not fit into the independence discourse promoted throughout VP.

SM   '*To be honest these new LDAFs (training modules, introduced by VP, (now discontinued) are mind numbingly boring.*'

SM '*If you had absolutely no awareness they might be a good start, but otherwise they're a compete waste of time.*'

SM '*Its just a stream of jargon, these trainers tell us nothing.*'

SM '*You know we had one the other day, came to talk about employment. I know she had no idea about our SU's. I sat there as she waffled on about getting into work, it was just so inappropriate and I was thinking, you know what, this probably cost quite a lot of money. We just had our budget cut and I was thinking the money they spent on her, could have provided some really lovely outings for our SU's.*'

It is not altogether clear why there was such disparity between the three centres. The answer may lie in the leadership skills of the managers. The OL manager was clearly passionate about her centre, passionate about what they could offer their SU's and passionate about developing her staff. She was the only manager who, for example discussed staff development with the researcher. The other managers referred simply to training days. When pressed it was unclear if the training days were a regular occurrence or not.

The OL centre staff presented the most cogent responses. They definitely understood their client group the best, from a clinical point of view. The staff at IL2, on the other hand, referred to their main client group with much affection, but little clinical knowledge. However their lack of understanding for their SU's with more challenging behavioural support needs was jarring. They over ascribed mental capacity to this group in a manner, which suggested the training they have is not adequate or even relevant.

The staff at IL1 were recruited from a larger pool of staff, when the previous day centre was closed down. This suggests a higher calibre of worker may have been retained, which in turn could account for their more thoughtful theorizing. The fact that one of the participants referred to reflexive practice, demonstrated at least, an awareness of this process.

6.6.6 Policymakers lack of understanding leading to uninformed planning

Participants at all three centres, expressed concerns with the lack of public awareness of the needs of people with PIMD. The staff at IL1, in particular have to deal with issues of general public ignorance daily. The staff at IL2, struggle to access public transport, whilst the staff at OL use the local Learning Disability forum as a space for raising the public profile of people with PIMD.

All three centres were aware of the lack of ongoing advocacy for their client group.

Workers at two of the centres (IL2 and OL) with experience of the 1980's closure of long-stay institutions, believe those transitions were better managed.

All three centres acknowledged there is poor transition from Children's to Adult services. And all centres acknowledged there is a much-reduced service nowadays. No service user at any of the three centres attends a five-day week. All managers reported this was due to oversubscription. And all managers pointed out they had historically provided a five-day service. The OL centre had the biggest increase (double capacity in four years).

All of these issues; public awareness, transport, advocacy, transitions, capacity and specialist services, could be resolved. However, the overriding concern from participants, that policy makers and planners did not even know that people with PIMD exist, might possibly be the reason for the concerns in the first place. (This echoes the comments of families interviewed and will be discussed further in the next chapter.)

The staff at IL1 take groups of people out most days into the local community. The town centre is within walking distance. They referred to many examples of negative public attitudes. They also pointed out,

SM ' *there's a lot of indirect discrimination that takes place out there. I'll give you a classic example. We went to this place, this pub. You got the feeling they weren't happy about people with disabilities being there. Their snacks were all around the £3.00 / £3.50 mark. That was great cos most of our SU's have about that for their spending. Well we went back, maybe a couple of weeks later …. And all the meals, snacks whatever; there was nothing under a fiver. So you see, they weren't stopping people, but that's what happens. In effect they barred them without saying they was barred.'*

This centre also takes a group to a supermarket café, as an outing. This is a longer trip to the other side of the borough, so they have LA transport provided. However, this is not regular and is entirely dependent on a bus being available. How SU's are meant to cope with such informal, open-ended arrangements is a real concern. It demonstrates clearly the lack of awareness of the needs of people with ID, never mind PIMD, at planning level.

When the discussion at IL2 turned to using public transport staff were unsure why they had to persevere. They believed the change was about cost cutting more than anything else.

SM 'S*ometimes I don't think those planners even understand there are people like our SU's.'* *…………… 'they come up with these ideas, like 'let's all catch public transport'. At the most you can get two wheelchairs on and if there are people already there with pushchairs, forget it, they're not moving them you know.'*

In the Foreword to VP, former PM Blair states that,

'*in a modern society …. everyone is valued and has a chance to play their full part*' (DH, 2001 p8).

Participants were asked what they thought he meant by play their full part. The manager of the OL centre responded thus,

SM ' *we believe our client group do play their full part, but possibly not the way that he means. They teach people about humility, about disability in general, just their presence raises awareness. This is why we always take them to the Partnership Board sub-groups and the Learning Disability Parliament.*'

It should be noted here that these Partnership Boards were the VP mooted mechanism for delivering services for people with ID locally. This was further emphasized in the refresher document VPNow (DH, 2009). Although the researcher did not draw her on this further at the time, it is clear the manager felt her clients needed to have their profile raised at the Board meeting, which discusses spending on services for people with ID generally. (This also chimes with comments made by parents in the previous chapter, about always taking their son to conferences and meetings, in order to promote the awareness that some people with ID are more profoundly impaired than the majority who can self-advocate). The deputy manager at the same centre recalled an advocacy service that had received some funding around the time VP was published. However, it only lasted for six months,

SM '*oh yes, that's long gone. There's nothing now*' (OL).

This was the feedback at both IL1 and IL2 also.

SM '*Yeah, where are the advocates? There are some at Mencap, but that's it, maybe two or three.*'

Transition from Children's to Adult's Services was also highlighted in VP. And yet, at OL,

SM '*Transition is still diabolical. They come with nothing there is no follow on. It's not like six weeks before they start, no, there's no gradual getting used to it. No coming with all their paperwork. Parents are lost as they are just told there is no service.*'

Although this comment is from the outer London group, it chimes with a family interviewed in inner London, whose son has recently transitioned to adult services (HN: 124).

And at IL2,

SM' *To be honest, I think much better work was done twenty years ago, on transitioning from long-stay hospitals.*'

Researcher ' *I wonder how aware commissioners are of this client group? Do you think senior people understand about their needs*?'

SM ' *Senior commissioners rarely visit and when they do, they seem uncomfortable. They don't know how to approach the SU's.*'

SM '*In my opinion, they don't want to know how long it takes to work with a client on an individual basis. They don't seem to get it, or understand.*'

SM '*Sometimes I don't think these planners even understand there are people like our SU's.*'

At IL1, the staff reported,

SM '*It just feels sometimes like we're going through the motions, but why? I know it's great for people to have more going on in their lives, to get out and about. But it needs planning. It doesn't feel like there has been a lot of that. The partnership board has all these ideas, but none of them seem to stick, do you know what I mean?*'

SM ' *some people, they think negative, but have never been to a centre like this. They don't realize they're making policies blindfolded, cos they're not really making policies for our SU's. They (the planners) need to be out there in the community, to see what life is like and then they can start to design services that will be suitable.*'

It was as this discussion panned out, that one of the workers came up with the sticking plaster analogy. She was concerned that there ought to have been more planning around specific needs of their SU's rather than the generalized approach, whereby they felt they just *'had to get on with it.'* Many of their clients were older and had arrived back in the borough after living in residential long stay accommodation for many years. These people were simply brought back one day and ensconced in their new home. There was no trial visit or general easement tactic to make the transition in any way understandable to them. The worker believed this approach had been detrimental to the individuals themselves, but also to the local community.

SM '*All these people have been brought out of those institutions, yes they were bad, very bad, but, they didn't make the right preparations. They've just been dumped on the community.*'

As she saw it,

SM '*they just stick a plaster, it's like they just stick it on the arm, without knowing what the wound was, or even where it was. You got to get in deep and clean it out first, then you can stick the plaster.*'

Another worker, at IL1, thought someone,

SM '*Should have told the community we were coming.*'

VP refers to community, however the community these workers are describing is not welcoming, has no changing rooms, no local specialist facilities, a real lack of specialist therapeutic services, no bases for when they are out and about, or as the workers at OL described it,

SM '*dragged around the high street or into Macdonalds*'

IL2 was the only centre with some SU's who had the behavioural support needs associated with ASD.

Researcher '*What about new specialist services, say for those people who present behavioural challenges*?'

SM '*we don't know about that.*'

SM ' *no, in fact at the moment there is nobody in post. I'm not sure what is happening*'.

Researcher '*I remember when the psychology service used to be on B Road. That's all gone now*?'

SM ' *That's long gone.*'

Researcher,' *So there is no current specialist service*?'

SM '*Uh, uhhhh.*'

Researcher ' *at least they have kept the day centres open, unlike some other boroughs.*'

SM ' *yes, but no one gets a full five day service anymore. Anyone new to services will get maybe one, two or three days at the most. Usually it's the two.*'

Researcher 'so what do people do the rest of the time?'

SM 'home innit.'

Researcher ' I wonder are commissioners even aware of this group. Do you think senior people understand their needs?'

SM ' Senior commissioners rarely visit and when they do, they seem uncomfortable. They don't know how to approach our SU's'.

SM 'In my opinion they don't want to know how long it takes to work with clients on an individual basis. They don't seem to get it or want to understand.'

6.7 DISCUSSION

The new approach of VP has been in service for a decade now, presumably long enough for the ideas to become embedded in practice. On the evidence of this study, it would appear this has only happened superficially.

The workers at one day centre in particular (IL 2), even stopped themselves mid- sentence and acknowledged they were meant to use different language now, but could not given any further explanation. They had been told the old terminology was no longer appropriate. They accepted this and didn't consider it any further.

The other day centre, in inner London, IL1, also acknowledged the change from 'disability' to 'difficulties'. Since they were in the same borough, a possible reason could be some new training initiative in social model influenced new language.

The fact that workers did not apply the same new terminology when describing SUs with physical disabilities, demonstrates how superficially they have been trained in the use of this language.

It was more difficult than expected, especially at the inner London centres, to draw staff on various aspects of VP. Most workers had little to no knowledge of the policy. This was not unexpected. Care is seen as relatively unskilled work. Qualifications such as NVQ level 2 are described as desirable in VP (DH, 2001 p98), although they do not cover ID or PIMD

specifically. The new Learning Disability Awards Framework was referred to by a worker at the OL centre as '*mind numbingly boring* '.

The idea of choice is certainly embedded, but it is questionable if the understanding of levels of choice making is any more than superficial. When the staff report they are asking SUs if they would like to go out to various places, they describe measuring changes in SUs body temperature. They believe they can use any changes in temperature to assess whether the SU wants to go out or not. This is a very muddled approach to the idea of proffering choice.

IL1 participants struggled to understand the concepts. Indeed they could be said to have hit a wall of not understanding, since these concepts did not make sense to them. Coincidentally this group encountered the most negative attitudes from the public, yet conversely were the deepest thinkers. They ended up creating a more psychoanalytic understanding; especially of the negative attitudes of the local general public, who are primarily African/Caribbean. It is unclear why they displayed more thoughtful responses than the participants at IL2. Perhaps the researcher probed more efficiently or had drawn on the experiences of previous discussions.

At IL2 the probing was most often concerned with getting the workers to re- focus to PIMD, rather than to more able examples. There may be more awareness of the diversity of the PIMD client group at IL1, due to their access difficulties. It is possible the workers at IL2 are more used to and more comfortable working with more physically impaired clients, than those with behavioural challenges.

The OL workers with the most pragmatic approach argued the VP agenda has little relevance for their service users. They were engaged from the outset, their comments were thoughtful and analytic. Hence they did not attempt the types of superficial choice activities that IL2 engaged in. Of course this is not to say, people at IL2 had no deep thought, or that OL workers did not acknowledge ideas of VP. At all sites the workers had to be drawn and probed. The study definitely needed two visits. Hence it felt like the first visit established what the researcher was seeking to discuss and on the second visit people could be drawn more. When re-reading journal notes made at the time, the researcher noted there was a definite feel at both IL sites of workers espousing the party line and possibly workers thought they were being tested on this. There was also a feeling of possibly distrust, evidenced by the lack of initial engagement and oftentimes, blank looks in response to questions.

On reflection this could have been be due to the workers wanting to be seen to say the right thing in front of management. Certainly the reason IL1 were so forthcoming on the second visit, could have been due to the absence of their senior manager. This visit was the most satisfying, due to the evolving discussion. The researcher was expecting more non-engagement and ended up having such a deep discussion, that staff were still walking down the road talking and discussing the issues after the formal focus group finished. This did not occur at the other sites to such a degree.

6.8 Conclusion

This chapter sought to answer the research question 'How knowledgeable are formal care workers, supporting people with PIMD of the VP approach? Is there any evidence of a theory - practice gap?'

The workers at the OL centre appeared to have the clearest understanding of just what PIMD is. And they were fairly clear that the VP agenda was not particularly relevant to their client base. On the other hand there was real difficulty ascertaining the knowledge IL2 workers had, regarding their client base. Unfortunately, as well meaning as their intentions may have been, their approaches do not appear to recognize levels of understanding or cognition. For their SUs who are at very early developmental stages with very profound physical impairments, someone directing talk and eye contact can be engaging and stimulating. However, constant questioning can be highly disturbing and frustrating for an individual who has some contextual cognition, but no means of responding or truly understanding. This can certainly result in the behaviours described as challenging and this centre did refer to a number of SUs who display these behaviours.

The workers at IL1 were focused overall on the lack of preparation they perceived. They felt a change in policy had been introduced, but they had to deal with the negative ramifications of this 'on the ground.'

All participants at all centres, at some stage, referred to the lack of awareness of their client base at policy making and planning levels. It is worth reiterating, *'if we do not know who we are talking about, how can we possibly know what the issues are?'* (Samuel and Pritchard, 2001)

CHAPTER 7

The Burden of Non-Productiveness

7.0 Introduction

The over-riding aim of this thesis was to increase awareness of adults with profound intellectual and multiple disabilities (PIMD). In addition it set out to challenge the prevailing binary definition within Valuing People (VP) of intellectual disability (ID) as being ID or severe intellectual disability (SID) only. It argues this is in order to better fit a social model discourse of independence, employment and mainstream inclusion. The continuing lack of an agreed universal definition of PIMD has ongoing implications for service design, provision and delivery. Moreover, in the new mixed economy of one-size-fit's-all planning, there is less capacity to meet the lifelong specialist, complex and individualised needs of this group. By positioning the research within an inclusive approach it was possible to develop a new, more meaningful way of including people with PIMD in consultation.

The re-conceptualisation of ID within a unified everyone can work approach (DH, 2009) is deeply problematic as previously noted. By insisting everyone has the potential for employment, it is then not necessary to discuss lifelong dependency and the support needs this entails. The idea that society needs to be protected from the burden of an individual's unproductiveness seems as current now as when the eugenicist Tredgold first made the claim in 1909 (cited in Concannon 2005, p14-15.) The question arises as to which section of the ID population the current policy was directed. By attempting to encompass the entire spectrum of ID, it appears the policy has not merely misrepresented people with PIMD it has failed to include them. This chapter will triangulate the main findings from the study in order to illustrate these concerns. It will commence by outlining the main findings of the critical discourse analysis (CDA).

The study employed methodological and data triangulation based on a CDA of VP, semi-structured interviews with family carers and film-elicited focus group discussions with formal care workers. Hence it was possible to compare the manner in which PIMD was represented (or not) in the formal policy with the ways family carers and paid care workers make sense of the policy, in relation to people with PIMD. In other words, PIMD could be thoroughly and

iteratively examined from the three diverse spheres of lay, workplace and theoretical. The value of a triangulated research design lay in the fact that it would uniquely afford a critical exposition of VP (DH, 2001), coupled with first hand accounts of the impact of this policy on families and practitioners.

7.1 Construction of target population/exclusion of PIMD.

CDA demonstrated the manner in which VP's proposals, echo at least three of O'Briens Five Service Accomplishments, which in turn echo SRV ideas (Race, 2003). They also parallel social model (SM) ideas, especially with regard to independence, choice and control (Morris in Thomas, 2007).

It further demonstrated the manner in which any reference to levels of impairment, such as profound and multiple, was excluded from the document. This was not a likely oversight. Fischer (2003) refers to the work of Schneider and Ingram (1993a), which analysed the way target populations for a particular policy may be socially constructed. VP (DH, 2001) clearly posits a construction of individuals with low levels of ID, who are in control of their lives. They can self-advocate, be independent, progress through learning and training and eventually attain employed status, thereby fulfilling their new social contract responsibilities.

The VP document points out that with rights come responsibilities. This is a reference to the then Labour government's Third Way policy, which sought to move away from the old passive style of welfare recipient to a new active citizenship model. As Powell (1999) pointed out, the citizen has a moral responsibility to work. This social integration discourse (Levitas 1996), which links inclusion to employment, coincides with the social model demand for equal rights including the right to work. The emphasis throughout is on these conditional rights. The right to work, the right to education, the right to marry, vote and express opinions. All of these are dependent on having the intellectual capacity to do so in the first place. They are also influenced by the original social model ideal of rights, leading to empowerment, which then leads to opportunities for education, training and the ultimate goal of employment.

Another aspect, which the analysis of VP's storyline revealed, was the manner in which people are encouraged to collude in a game of pretence. A narrative is written in the first person, to illustrate one of VP's big ideas, as if the individual themselves had said it. This is problematic for many reasons, not least of which is the failure to acknowledge individuals who cannot self-report. The policy promotes a person centred approach, but the person must fit a certain ideal. The narratives are presented in the style of good news stories and the good news is always focused on what can be achieved via empowerment and self-advocacy. The policy purports to herald a paradigmatic shift from the medical model to the social model of disability approach. However, based on the findings of this study, the shift merely represents a transformation of language and discourse. It is not apparent that changing the language will change social practices.

The muddled representation of people with PIMD in the various Department of Health (DH) papers (DH, 2001, 2009) appears to have been a well-intentioned attempt at using an innovative social model approach. Unfortunately, in the rush to avoid discussion of individual embodied issues, the reality of PIMD has been lost. Further, by not acknowledging an individual's dependent status, the work of family carers and formal paid care-workers becomes even less visible. This in turn leads to, amongst other issues, lack of support, low wages, poor staff retention and staff / family burnout. These issues were all raised during family interviews and the focus group discussions.

7.2 Family carers'/care workers' concerns about the impact of VP policy.

There were references throughout the VP document, which supported the notion of a constructed target population. Family carers expressed a concern with, what they saw as the documents over emphasis on people with more ability. Careworkers, especially at the outer London (OL) centre, took the approach that the document did not have much relevance for their PIMD client group. The trickle down effect of this emphasis was also evident in the later discussions with paid care workers at the inner London (IL) boroughs. Their confusion about levels of ability of their clients was understandable. VP was telling them, for example, that assistive technology can improve cognitive functioning (DH, 2001 p52 4.3.1). Likewise with the constant use of words such as may as in '*may have difficulty communicating* '(DH, 2001 p101 p 8.34). Individuals with PIMD will always have this difficulty and as such there

is no grey area. Equally there is no discussion about whether they '*may need support*' (DH, 2001 p101 8.34). It is clear they will need it. By insisting on these loose caveats the impression is given that perhaps an individual may not have difficulty or may not the need the support. If the careworkers at the specialist day centres found this confusing, it is hardly surprising the generic agency workers appeared to have so little understanding.

Testimonies from family carers and paid care workers corroborated the findings of the CDA. This clearly illustrated the negative impact the exclusion of PIMD has had on the lives of individuals who might be described as a minority without voice, within an existing minority. The goal of VP was for all people with ID to be included in the mainstream. By improving access to mainstream health, education, housing and employment, VP argued, the greater visibility of people in the community would allay ostracism and negative public attitudes. Unfortunately these goals relied on the VP discourse of all people with ID being able to '*move on*' and '*be independent*' (DH, 2001 p23), attend college/training courses (DH, 2001 p77, 86), and '*move into employment*' (DH, 2001 p76). The objective failed to account for those whose specialist needs could not be met in the mainstream.

There was a clear consensus from families and care workers, in both boroughs, about the lack of awareness and understanding of the needs of those with PIMD at policymaking level. This echoed the CDA findings. People also believed the lack of understanding, was reflected at the level of local commissioning. The main issues, raised by families were to do with a lack of services. This was not unexpected, as the CDA revealed the one area of VP, which had no accompanying objective, was the section concerned with specialist services. Family carers referred to the lack of specialist health services, particularly physiotherapy and specialist support especially in light of the move to informalised community service provision. Residential respite was a major concern, as was the lack of choice of service, service provider, support worker or travel escort. Families of Asian origin in the OL borough did not believe their cultural needs were understood either. There were no comparative complaints from families of African/Caribbean origin in the inner London borough suggesting the IL borough has a more effective cultural awareness programme in place across services. It could also mean families have simply given up complaining.

There was a reported reduction in services over the last few years alongside a general feeling that existing services were not improving. Families believed this could be attributed to the use of generic agency workers. This included the concern that workers were unskilled,

especially when working with people whose behavioural support needs are described as challenging. A number of carers in the OL borough reported a take it or leave it attitude from their local authority (LA) when any service was queried. Most families felt pressured to take up Individual Budgets (IB), however only one family in the IL borough had exercised this option.

Families described their caring responsibilities in terms of battling or fighting for services. The carers interviewed, ranged from those who were very well informed to those who were resigned and overwhelmed by years of constant caring. The former actively lobbied by sitting on various Boards and sub-groups concerned with ID and PIMD. The latter had actively withdrawn from participation. These families presented an almost siege mentality by refusing any services or help. '*Tired of fighting*' was an expression used by most of the families. This fatigue included the constant consultations they responded to with no discernible results, with families querying what they had achieved. Those who were active on their Learning Disability Partnership Boards (LDPB) believed they had had little effect. They reported that all decisions were taken at a higher level, where carers did not have a voice or vote. A number of the carers in the inner London borough described their constant input to the local Partnership Board as a waste of time. They questioned the role of the Board, believing it to be merely a talking shop, since no strategic decisions were made there. For this reason, they felt their influence was minimal.

Carers in both boroughs did not feel their views were heeded. Their responses were framed in replies, which suggested their concerns were falling on deaf ears. There was a definite feeling that their constant lobbying was ineffectual. They reported meetings with commissioners, who sat and listened, but did not make notes or keep any written record. The carers were trying to discuss their dismay at the move to informalised, outsourced services and the extensive use of agency workers, but felt no one was paying attention to their concerns. They expressed a concern with constantly changing personnel at senior commissioning levels. Each time someone new came into post, they felt they had to start lobbying all over again to apprise the new personnel of the specific needs of those with PIMD. This concern was further borne out in the focus group discussions with careworkers.

There were a number of areas of disconnect with the CDA of VP. One of the families interviewed, explained that they had queried the exclusion of people with PIMD from the policy. Their LA had advised them that all of the objectives, promoting delivery of VP aims

applied to all people with ID and this included those with PIMD. This seems a disingenuous explanation. As was demonstrated by the CDA, the various objectives were associated with the overall aim of mainstreaming services. There was no specific objective associated with the delivery of specialist services. However, most of the families interviewed discussed their need for and the local lack of these specialist services. For example, families in both boroughs cited the historical lack of funding, recruiting and retaining of specialist physiotherapists. Families gave graphic examples of the physical problems that resulted from this glaring need. These included long-term loss of bodyshape, severe spasticity, pressure sores and respiratory illness.

In the outer London borough, the families who were lucky enough to have even one day's attendance allocated at the specialist day centre, could then access the specialist physiotherapy service. Unfortunately the centre, which the manager explained had been purpose built for twenty-four people, was now oversubscribed with more than one hundred clients. This means that those new to adult services are being placed in the generic alternative. This is a much less formal, community based service without specialist therapeutic input, as there is at the oversubscribed centre. Families felt they were being pressured to accept more informal and therefore unsuitable services. They were concerned their sons and daughters needs were being overlooked and disregarded.

VP's objective that mainstream health services ought to be available to all has not been realized for the majority of people with ID, let alone those with PIMD. Indeed it cannot, since mainstream services do not cater to or offer more specialist services. A number of families confirmed this in interview. Families were also concerned that staff had no specific training in autistic spectrum disorder (ASD) issues; their concerns were confirmed in the later focus group discussions with workers at the IL2 centre.

Families in both boroughs reported a reduction in service and this was borne out in discussion at all three-day centres. No one accessed a day centre five days a week, as they used to, the average nowadays being one to three days a week. Families interviewed in the OL borough were mostly receiving the newer more informal services, provided by local care agencies. They reported less one to one provision in their care packages. These reductions inevitably meant some people were spending more time at home, thus increasing the already burnt-out families caring responsibilities. Families overall believed services were getting worse rather than improving. There was a concern that agency workers and transport escorts were not

trained to support people with ID, let alone the more complex issues of individuals with PIMD. Even allowing plenty of time was impossible, as workers were always rushing to their next appointment.

Considering that most of the families interviewed provide between 40 and 160+ hours of unpaid care, per seven-day week, it is not surprising that respite is so important. Unfortunately, the families reported the vague wording of breaks in VP (DH, 2001 pp 19, 30, 48, 57) has meant LA's can fulfil their requirement, by simply renaming services. Hence attendance at a day centre may be described as a break for the carer rather than a service for the adult. In the inner London borough carers meetings and coffee mornings are even described as carer's breaks. The inner London borough also has a historical problem with residential respite, which had been unavailable for over ten years. The primary form of respite on offer in both boroughs was a home sitting service, whereby someone would come and sit with the individual, whilst carers went out for a couple of hours.

This again was evidenced in the CDA of VP. One of the good news stories (DH, 2001 p 55) clearly promoted this new style of respite, as being an improvement on residential respite. This type of informal service might well be appropriate for those with lower levels of need, looking for an alternative and flexible service. However, the idea of the individual having respite care provided in their home, presupposed the family carer(s) were well enough and had somewhere, or could afford to go somewhere for their own break. Also, a number of families described the positive side of residential respite for their son or daughter, as being one of opportunities for experiences outside the home. All families interviewed describe their need for residential respite and all families either reported difficulties in accessing this, or a concern with the ad hoc nature of breaks provision. As they pointed out, it can take years for people with PIMD to build a relationship with supporters. They questioned how this was possible, if they were simply offered a few days break when and if there was a suitable opening.

VP discussed and promoted Carer Assessments, but family carers who had received one, described the benefits as negligible. Those interviewed in the OL borough confirmed the assessments were only now being introduced, ten years after publication of VP and fifteen years since publication of the Carers Recognition Act. VP went to great lengths to describe the '*lifelong commitment*' carers make (DH, 2001 p53). They are described as '*a crucial resource*' due to the '*vital contribution they make*', which includes '*providing most of the*

support' (DH, 2001 p53) and yet one very relevant piece of information was excluded. Carers of adults do so voluntarily. The statutory responsibility for those adults who lack the capacity to care for themselves lies with the state, not the family (see for e.g. Clements, 2012 pp37-38). Families in both boroughs believed they received less help because their LA's presumed they could depend on them to keep providing care.

It must never be assumed that carers can or will provide care. Carers can choose whether or not they will care and the level of support they are prepared to offer. The amount of caring they can and are willing to provide must be negotiated and regularly reviewed

Another area of disconnect between VP aims and family carers' experiences, was personalisation. The use of individual budgets (IB) was a key aim of VP. This was the route to *'enabling individuals to have more control over their lives'* (DH, 2001 p44). It is not surprising therefore that most families had been offered this option. Only one family however, had embarked on this route, via a local provider. They recognized it was more work for them, but they were conflicted as the outcome was positive for their daughter. Families, overall, felt they were being pressured into taking this option and were adamant they did not want to. IB's are seen as a way of empowering service users, (SU) by drawing up their own support plans and recruiting and managing their own personal support workers. However it is not surprising so few of the families interviewed have taken up this option. Whilst it may well be a viable option for someone with capacity, in the case of an individual with PIMD, the work would, yet again, fall to the family. The family would become the unpaid social worker and care manager as well. It is no surprise that LA's are enthusiastic about an approach that has to be a cheaper option when taking this into consideration. The families who believed VP was a cost cutting exercise referred to this as an example.

Families with younger adult children were bewildered by the lack of preparedness for their transition to adult services. Family carers and care workers in both London boroughs raised concerns about this. Family carers talked about the lack of services and in the focus group discussions, careworkers described the manner in which new clients were arriving with no planning or background information. Unfortunately VP's focus for the transition years was on the delivery of education, training and employment. Family carers believed this was evidence of the low priority people with PIMD had within the overall policy. They also felt it demonstrated their views, in consultation, were not heeded.

When the discussion turned to one of the big ideas of VP, which was the concept of choice, there was a clear difference between VP, families and care workers. Families overall and the OL care workers adopted a more realist ontological / epistemological stance. This is the view that something (in this case PIMD) exists independently of being perceived. The families made statements such as (*'you can't change biology or whatever it is'* (SB:I, p128), or '*… H ain't never gonna be independent, she can't make choices, she don't have control of her body, or you know her bladder, never mind her life'* (SF:I, p137). This stance chimes with the ideas of Vehmas and Makela (2010) and Kittay (in Carlsson, 2010), which were discussed earlier (C3 p68). Families described expressions of choice being made through body language and behaviour, but importantly they felt staff often ignored or misunderstood these cues. They referred to minute pockets of autonomy and as demonstrated by the film elicitation, believed these meaningful, albeit contextually dependent choices were overshadowed by bigger less meaningful ideas. These views and concerns were at odds with VP's contention that everyone can make choices.

Another aspect of choice outlined by VP, was choice of support. Even though staff at IL2 insisted all SU's had a choice of supporter, families in the same inner London borough reported lack of choice of service, support worker and transport escort. In the OL borough families also reported lack of choice of provider and support worker. These findings demonstrate an overwhelming lack of fit between VP's aims and the families' reported lived experience. Schwandt (cited in Denzin & Linclon, 2003 p193) refers to the way critical methodologies are preoccupied with reducing illusions in the human experience. VP could be accused of creating an illusory and idealized representation of ID, which holds little relevance for the families interviewed and has led to some confusion for the care worker's understandings of their client group.

As stated there was general agreement amongst care workers across all three sites, that policymakers seemed unaware of the needs of people with PIMD. The constant refrain of, *'they don't get it',* was voiced by family carers and care workers alike. This included managers. It is a contention of this study that the lack of awareness at commissioning and policymaking levels impacts negatively at practice level. This was confirmed by some care worker's use of approaches, which were at odds, with the mental capacity of service users. By promoting generalised ideas and insisting they are applicable to all people with all levels of ID, VP is inadvertently causing 'on the ground' difficulties for carers, care workers and

service users. These difficulties were compounded by the concerns of paid care workers that the new approach was not reflected in public attitudes.

7.3 Care workers' film elicited comprehension of VP policy.

The discussions, based on the film elicited focus group, sought to ascertain the care workers understanding of the approaches inherent in VP. By representing the big ideas of VP in the filmed excerpts, the study further sought to draw out care workers examples of these ideas in their own practice. The subjects of choice and inclusion drew most discussion, whilst ideas from VP such as first person narrative reporting and the proposed use of assistive technologies were referred to. Social model influences were apparent in the use of language and the absence of discussion of levels of impairment. Many of the workers spoke in the language of VP, particularly at the IL2 site. They seemed to have adopted or were in the process of adopting the new language, with little underlying understanding of the concepts or rationale for doing so. This was alluded to by family carers who were unhappy with the new professional language they believed was being used.

Staff at the OL centre were the most informed and able to refer to their own specialist knowledge of PIMD. They demonstrated an understanding of their SU's levels of mental capacity and the impact of this. Much like the families interviewed, they discussed concepts of choice as subjective assessments the worker's made, based on assumptions and observations. In contrast, the workers at IL2 had little understanding of the meaning of choice for their SU's. The staff at IL1, though, were very thoughtful and eventually reasoned that their SU's were unable to make clear cut choices, due to their development age. The workers at IL1 and OL were keen to point out that acknowledging this mental age did not mean they infantilized their SU's.

When the workers at IL1 referred back to the film, they recognized the individual's actions were contextual rather than based on verbal understanding. This observation led them to change the word from choice to preference, as they felt choice was a more conscious act and therefore required higher levels of cognition than the SU's they were referring to. This was a good example of emergent thinking arising from watching the film.

When asked for examples of someone having more control over their life due to the introduction of more choice, it became apparent they had no knowledge of levels of choice or informed choice. On reflection they later agreed the SU's change in behaviour was most

probably due to receiving more one to one attention than open-ended choices. This was another example of emergent thinking prompted by the film led discussion.

Families' concerns about care workers missing body language and behavioural cues were confirmed during the focus group discussions. The lack of understanding about levels of communication was most prevalent at IL2. Research has demonstrated the manner in which staff tend to overestimate SU's verbal comprehension skills (Bradshaw 2001, Banat et al 2002). Whilst parents were concerned this was due to a lack of training, it could be the staff are being trained in newer, more generic approaches rather than being PIMD specific.

Staff had assimilated lots of words and phrases, without necessarily understanding what they meant. This could be why some parents reported the communication books which travel home with SU's, seemed to use more professional language. The constant reference to health and safety issues would suggest litigation averse LA's. Ultimately the families felt the new language created a tangible barrier between the SU's and their support workers.

The first person narrative approach, employed by VP, whereby statements are purported to be the views of individuals, has now trickled down to practice and was described by care workers at the IL1 day centre. They have to fill in forms as if the service users have done so. The items described include, strengths, needs, interests and aspirations. This account then informs service delivery. With information provided by family or support workers who know the individual well, it might be possible to draw up a list of interests. Unfortunately, as the workers at OL pointed out, these can too easily become set in stone, when likes and interests can and do change.

Staff at both inner London centres corrected themselves a number of times when using the term learning disabilities, by stating they had to use the new, friendlier term learning difficulties. They could not explain further, which again demonstrates the way they appear to take on board the language of VP, with little depth of understanding. Regarding a query as to how they consulted SU's about their choices, which they had explained were kept in the individual service plans, (ISP) the researcher was advised of yet another training course where they would learn how to enable their SU's to communicate. When probed, they spoke about assistive technology and software programmes. It sounded as if they were repeating phrases, which had been used to illustrate training sessions but unfortunately they were clearly incorrect. There is no training module in existence, which can enable anyone, much

less individuals with profound intellectual disability, to access communication skills. The CDA of VP also revealed this anomaly.

One of the main features of profound ID is compromised communication skills. These individuals' intellectual development is at a pre-intentional and pre verbal stage. This means they do not have the intellectual capacity to represent words and therefore develop this skill into language. Unfortunately, not only are the staff being advised they can achieve this with their new tool, they are also being misinformed about what can be achieved with assistive technology.

7.4 Care workers' lack of specific training

The issue of unskilled workers receiving minimal training cannot be ignored. A recent study in Belgium, for example (Hostyn et al 2010) involving workers supporting people with PIMD, described their educational levels. The vast majority had university degrees and a background in special education, whilst the most prevalent qualification in the UK at the time this study was conducted, was the National Vocational Qualification Level 2 (Dobson and Myers, 2006). The majority of the day centre workers had or were working towards an NVQ level 2 /3 whilst two managers had a NVQ level 4 (Appendix D: p261). The OL agency staff (as opposed to the OL day centre workers) clearly lack basic training. It was not possible to clarify what qualifications they held if any. Their use of terms like challenging echo the IL2 staff, who displayed little understanding of challenging behaviour generally, or within the context of ASD. Family carers' concerns that specific support strategies were not enacted were confirmed. As were their concerns regarding the statutory guidelines associated with the Autism Act (2009).

The VP promise of a skilled, trained and qualified workforce was only evident at the OL centre, which is no longer accepting referrals. Families raised concerns about the poor quality of the replacement agency service. They echoed inner London families' concerns regarding personal care. Discussion with staff at IL2 revealed they believed by leaving someone to attend to their own personal care, they were encouraging independence. This is an example of the ideas of VP impacting negatively on practice.

The inherent contradiction of VP is that it advocates a person-centred approach, yet it maintains that everyone can access mainstream services. This has trickled down to practice level and is evident in the muddled thinking of poorly trained staff, being instructed to carry out a one size fits all approach.

When discussing the actions of the filmed individual, all three centres claimed they would not have the time or wherewithal to encourage the same actions. This may have been due to the physical nature of the various care settings, but it further demonstrates the difficulties with accommodating people with varied complex support needs. This further highlights an issue, which has not been discussed in the literature. Although it has been referred to by Sherborne (2001).

Within the world of PIMD, there are now two very diverse groups, those who are profoundly physically impaired in addition to their intellectual disability and those who have the emotional and behavioural difficulties associated with autistic spectrum disorder (ASD) combined with their intellectual disability and additional impairments /conditions/disorders.

Historically, as the name implies, the demographic was mostly comprised of people with profound motor and learning disabilities (PMLD). However, there are now more people surviving with a range of complex health and behavioural needs. Sherborne (2001) describes the way

'life can be made more difficult for those who work with people with PMLD if one or two in the group are not physically handicapped and are mobile but have marked emotional or behavioural difficulties' (Sherbourne, 2001 p92).

Put bluntly, overstretched staff with no specialist psychological expertise will construct defensive anxieties to cope with behaviours of particular service users. This was clearly evident at IL2. Working with this group of people can be very difficult and in the absence of real understanding of the implications of various conditions, it is easy to fall back on personal assumptions and attitudes. Workers need to have specific training in these areas, if they are to provide adequate support. It is unclear whose responsibility it is to ensure agency workers for example, have this specific training.

7.5 Negative public / cultural attitudes

The staff at IL1 experienced the most negative attitudes from the public. They had obviously not had an opportunity to discuss this reflectively and would no doubt benefit from similar sessions in the future. The opportunity led them to produce the more emergent thinking of all the care workers. Whereas the workers in OL had discussed cultural attitudes to disability in general, this group honed in on the very specific treatment of people with ID in Jamaica. In common with other communities, people there were incarcerated in institutions, but uncommonly, the rest of the family were not told. Often the only time they found out was when they attended their sibling's funeral. This culture of shame must still impact on people and it certainly helps to explain why the workers reported they were often accosted by older Jamaican people in the street, with accusations of '*why isn't he in a home.*'

In the ten years since the policy was introduced, rather than a diminishing of ostracism as VP predicted, careworkers at all three sites reported a rise in negative public attitudes. This has also been reported nationally (Mencap, 2005) and has accompanied an unprecedented rise in disability hate crimes (Riley-Smith, 2012). It suggests that whilst there may have been reported improvements in the public's attitudes towards disabled people generally, the picture for those with ID, including more severe levels, such as PIMD, has remained much the same. The work of Bion (1962) or Menzies (1960) suggests if anxieties are merely being suppressed, individuals and organizations (and the general public) will develop social defences in order to contain these subconscious concerns.

7.6 Negative impact of absence from policy

All of the issues raised by families and the focus group discussions concerning public awareness, transport, respite, transitions, specialist services and specialist training could be resolved. However, the overriding concern from all the participants, both family carers and paid care workers was that policy makers and local commissioners did not seem to be aware that people with PIMD even exist.

The lack of representation within the VP white paper has been documented. In fact when the policy was refreshed with the publication of Valuing People Now (VPN) in 2009, Chapter 1 was called 'Including Everyone' and '*people with more complex needs*' were top of the list

(DH, 2009, pp 29-30). The writers also provided a definition of complex needs, which included '*people with profound and multiple learning disabilities* ' (DH, 2009, p38) Finally, they appeared to recognize this group, although they insisted on the added caveat that '*people's needs are not fixed*' (DH, 2009, p38). It could be argued that an overriding general need for full support in every aspect of one's life is actually a fixed need.

VPN also still insists that the goal for these people is *'living independently and having paid work'* (DH, 2009 p31). So in a sense they are recognized, but they have to fit the model of the new social contract, which proclaims everyone has a moral responsibility to work (Powell 1999). This raises the worrying concern that those who cannot work are then assigned to the same category as other economically inactive citizens. The feckless scrounger discourse has been increasingly applied to everyone described as longterm unemployed, including those with disabilities (Garthwaite, 2011). A recent discussion with a head of learning disability services confirmed this. He argued that, whether an individual is aware of taking part in employment is not the issue. He advised this researcher that in order for an individual to have any value in society, they must be seen by society to contribute. This clearly harks back to Tredgold's turn of the century concern with '*the burden of their non-productiveness*.' (Cited in Concannon 2005 p14).

7.7 Triangulated evidence

The first research question asked, 'To what extent is current policy for people with PIMD, informed by the social model approach to disability?' The answer is not straightforward, since the policy under scrutiny here, does not actually acknowledge PIMD. It could be argued, this is because the policy uses a social model approach. And, as has been shown the social model outlines the manner in which society disables people with impairments via societal structures and attitudes.

The evidence has suggested that VP policy is probably best described as informed by a social approach, which includes ideas from earlier notions of normalisation. Unfortunately this presents difficulties accommodating everyone. Especially those people for whom all the positive attitudes in the world and all the physical or intellectual provision of access, will still mean they are entirely oppressed by their own biological issues.

As an example, Odyssey, the woman featured in the filmed excerpts has multiple diagnoses that are a part of who she is. It is not possible to disentangle the woman from the blindness. She has been totally blind from birth due to a rare congenital neurological eye disease. She has no optic nerve. This means, it is not possible for her eye to traduce the light inputs into electrical currents and hence form images in her brain. She also has diagnoses of ASD, cerebral palsy, epilepsy, intellectual impairment, polycystic ovary syndrome, hyperacusis, sensory integration disorder and a non-specified skin disorder. All of these conditions are also a part of who she is. Of course, she is also a beautiful, musical, lively, affectionate and vital young woman. However, to deny her challenges and profound difficulties is to deny her personhood. Acknowledging the whole person, means acknowledging her dependence and this acknowledgment and acceptance has to be empowering. Carlsson (2012) confronts this by suggesting there may be,

'dimensions of severe intellectual disability that will always lie beyond the philosopher's epistemological grasp' (p204).

The second question asked how families made sense of the philosophical underpinnings of VP. Family carers demonstrated an ontological grasp of PIMD with their responses grounded in a realist approach. It was not surprising they were oftentimes, rather scathing about the social model informed objectives of the policy. Their lives were very focused on dealing with the here and now, the struggle and effort to merely manage day to day. Therefore abstractions about idealized futures seemed rather fanciful to them, when for example, they could not even access regular physiotherapy sessions. Only one of the families interviewed had heard of the social model approach to disability before. They were more than willing to explore ideas about how to accommodate social model approaches, but ultimately believed VP had skirted the issue of PIMD.

The final research question had asked how formal care workers reconciled their own understanding with the new approach. By using the filmed excerpts, it was possible to elicit their genuine insights as opposed to the language of VP, which was so apparent at IL2. There was a very clear difference in responses from staff at the three different centres. Reasons for this could be to do with the very specialised nature of the work at the OL centre, as opposed to the range of challenges the service users at IL1 and IL2 presented. Unlike the inner London centres, they summarily dismissed VP as not being relevant to their client group. They referred back to the film mostly when the discussion turned to SU's levels of

understanding. They were the only group to notice, for example, that the woman in the film only appeared to understand. In the excerpt, which was meant to illustrate the concept of choice, they pointed out her ambiguous behavioural responses were actually only contextual.

The emergent thinking of the workers at IL1 developed from a rather lively discussion between each other during which they reconciled their own understandings with wider cultural implications. Many of the workers at IL2 tended to over ascribe mental capacity, but believed they were delivering the VP core concepts nevertheless. All centres advised they could not provide the one-to-one support the woman in the film was receiving. This led to discussion about what they believed a person-centred approach entailed. IL2 workers were unable to recount any examples in their own practice. Whilst the staff there remembered various words and phrases from training sessions, the ideas that informed these concepts were not embedded in their day-to-day practice.

7.8 Implications for services for people with PIMD

The data from the family carer interviews and film elicited focus group discussions has confirmed the CDA's demonstration of the limitations of VP, with regard to individuals with PIMD. As discussed the policy was published at a time when services were informed by a mix of approaches described as normalisation and these ideas do surface in VP. Ultimately this thesis has demonstrated the need for a comprehensive understanding of the issues associated with this demographic's specialist support needs. Airbrushing those needs out of the picture has resulted in confusion and frustration on the ground, as evidenced by data from the paid care workers and the families. It has also enabled the rolling out of top down one-size-fits-all approaches, which deny the particularities of need associated with this group of people. The triangulated methodological approach to this study was very effective in revealing this mismatch between the overall aspirations of the VP policy and the on the ground impact on the lives of those with PIMD and those who care for them.

Chapter 8   Next Steps

When this thesis commenced the UK was experiencing a period of welfare reform under New Labour via Blair's (1998) Third Way. As it draws to completion the political landscape has changed. Now it could be argued the situation is not one of reforming, rather we are seeing the restructuring of many aspects of the welfare state. The UK Coalition government intend to abolish disability benefit, council tax benefit, severe disablement allowance, housing benefit and income support. These will be replaced by one benefit called a Personal Independence Payment (PIP). The negative financial implications of this for people with PIMD are far from clear, as the government has not guaranteed people will not be worse off (CarersUK, 2013).

The implications of the ongoing marketisation of social care are critical for people with PIMD. An example of this can be seen in the OL borough, where the manager of the specialist day centre confirmed attendance is now at least four times over the original capacity. Rather than building a new centre, the LA had begun the process of outsourcing to private companies. New referrals are being offered the more informal, domiciliary service provided by agency workers from the newly set up Local Authority arms-length trading company. The families are allocated to an agency, with no choice. The workers are unskilled and untrained in specialist approaches for this client group. Redley (2009) argues that services are now

'being consolidated in the hands of fewer and larger providers', who `are 'subject to economic pressures to be efficient' (p499).*

The carers in the inner London borough reported reductions in service evidenced by reduced attendance at the day centre. Distrust of individual budgets (IBs) was apparent in the family carer interviews. Only one family had chosen this option and that had been a pragmatic decision to ensure their daughter had some continuity of care, when the local historical provider, was outbid by a newer conglomerate. All families in both boroughs reported pressure from their LA to move onto IBs, but the majority were adamant they did not want to take on the extra work. This would involve recruiting, inducting, training, developing and managing a team of workers.

Families believed they had already saved their LAs vast sums of money, by caring for their children at home all their lives. They believed they were in effect being asked to replace care managers at no cost to the LA.

Families in both boroughs were concerned that there was a lack of communication between themselves and service planners. Parents who sat on their Learning Disability Partnership Boards as carer representatives, expressed doubts as to the efficacy of the Board, since it had no strategic function. This fits with Bochel et al (2008) who cite lack of a voice and query who represents those with PIMD. Families were especially concerned about who would represent their sons and daughters interests once they were dead, whilst care workers were concerned that the needs of those with PIMD were overlooked in the new approaches to service delivery.

Day centre care workers (including managers) in both boroughs, felt service user needs were not properly understood by senior management or service commissioners. The day centre where workers had the keenest understanding of their service users (dis)abilities, rejected the cornerstones of VP outright, maintaining they held little relevance for their group. Wing (1998), Carnaby (2001), Burton and Kagan (2004), Henley (2001, 2005), Mansell (2007), Byrne (in Carlsson, 2012) have all expressed concerns that specialist needs are unmet by the new policy and have argued for differences to be acknowledged. Data from family carers and care workers confirmed these concerns. The findings echo Concannon (2005) who has further demonstrated the need for differences to be acknowledged in policy development which impacts on people with PIMD. He points out that those who make

'substantial claims for the possibility of communication with such people, seriously underestimate the problems involved for anyone without extensive knowledge of the individual concerned' (Concannon, 2005 p172).

Family carers and paid care workers were adamant about how long it takes to get to know an individual with PIMD and to build some kind of relationship with them. Staff need to have an understanding of what PIMD means for the individual, as well as levels of communication ability, in order to engage with their sons and daughters. The family carers were not confident that staff had sufficient training to meet these needs.

This exploratory thesis also sought to untangle some of the confusion around definitions and demonstrated that the term learning disabilities is used interchangeably with the term learning difficulties. This causes confusion internationally, especially since the two terms have the opposite meaning in the US to here (Leyin 2010). The thesis further argues that the blurring of definitions and use of deceptive language may over-ascribe mental capacity to people with PIMD, which has negative implications for staff interactions. The data show workers' lack of understanding of the various terms they used. Their use of the language of VP (e.g. choice, person-centred) demonstrated little underlying cognizance of conditions necessary for choice making or what it really means to place an individual at the centre of one's service.

Goodley (1997, 2001, 2004, 2011) Goodley and Rapley, (2001) Rapley (2004) and Williams (2006) use a social model framework, but only engage in research with participants at the milder end of the ID spectrum. Whilst Williams (2006) does refer to people with PMLD as a distinct group from those with ID, there is rarely such a distinction in the published literature. In fact this thesis is unique in focusing entirely on the manner in which social policy impacts on this demographic group. The aforementioned writers argue against a naturalized perception of intellectual impairment, which they claim to be oppressive. This thesis claims it is in fact oppressive to disregard the totality of an individual's life experience. The subject of the film used for the focus group discussions is a woman with multiple impairments and these all contribute to her whole persona.

This thesis is not arguing for normative commitments, rather to an all- encompassing, breadth of human experience approach, which acknowledges differences, including intellectual diversity. For this reason the ontological approach had to accommodate a realist element, as I wanted to demonstrate a materialist acknowledgment of PIMD. This is not to say the thesis is promulgating a medical model idea of fixing the individual. It is more about accepting the individual has a right to specialist inputs, which might ameliorate the negative impact of profound impairments.

As the families pointed out, no one wants to constantly describe someone purely in terms of their deficits. However, as was demonstrated, not acknowledging levels of cognition, for example, can result in poor interactions and therefore a negative experience of support between staff and service user.

Overall families were pessimistic about the future. One family member pointed out that services had gone full circle. He recounted the manner in which forty or so years ago, parents of people with ID had set up groups in church halls in order to provide group activities. He is in the process of doing exactly that, all these years later and queries if this is progress.

The literature review explored the way language carrying an emotive meaning is exploited. Hence words like segregated and institution carry ominous overtones, whilst certain ideas become simplistically dichotomized. For example, Social Model = Good, and Medical Model = Bad. The review further demonstrated the rise in numbers of people with PIMD and the attendant lack of social care funding.

The thesis finally queried why there have been so many historical changes in name and definition of ID. It suggests the constant renaming and deconstructing represent defensive manoeuvres, employed by a society struggling to accommodate this section of our humanity. In order to countenance this clear definitional language was used throughout. The acknowledgement of an individual's PIMD was considered to be emancipatory.

The inclusion of an individual with PIMD in this study, in as meaningful a manner as possible, was considered vital. The use of filmed excerpts arguably disrupted the illusion of lived experience portrayed within VP. Schwandt (cited in Denzin & Lincoln 2003, p193) maintains these illusions (here the manner in which people with PIMD have their experience represented within a framework of independence) need to be systematically investigated. This disruption grounded the discussions and therefore the study in a critical realist approach. The semiotic focus on the research problem interpretively explored the lack of fit between the underlying philosophy and ideology informing the VP agenda and the needs of people with PIMD. Currently, a kind of semantic trick becomes necessary, whereby people are described as having self- advocated, been consulted or designed their own service. They have not. Assumptions have been made by people who know them well and who can make proposals in their best interests (Mencap, 2011). This, however, is one step removed from an individual doing something themselves and needs to be acknowledged as such.

8.1 Recommendations

This thesis has raised a number of recommendations for meeting the specialist and diverse needs of this group of people.

8.1.1: Representation

An overriding concern raised by family carers and care workers alike, was that policy makers and local commissioners were unaware of the distinct needs of people with PIMD. Innovative ways need to be found to address this knowledge gap, as current methods for raising this awareness, are not conveying the message clearly enough.

The use of film elicited focus group discussions may be more effective. Sessions could be conducted with, for e.g. policymakers from the Office for Disability Issues (ODI). Their report '*Fulfilling Potential Building a deeper understanding of disability in the UK Today*' (DWP, 2013) was only very recently published. However, it ought to be noted that the claim in the title is not borne out by the content, as there is no acknowledgement of people with PIMD at all. The focus of the report instead emphasizes the fluctuating nature over the life course of many impairments. There is no discussion whatsoever of the enduring cradle to grave needs of this group of people.

The use of film elicited discussion, would be immensely helpful for those who may never have encountered people with PIMD and therefore would have no insight into their lived experience. This representation could also be encouraged locally. Many of the family carers expressed concern that their Learning Disability Partnership Boards were not strategic. They worried the meetings were merely a talking shop, with no real power. Dedicated representation on the new Health and Wellbeing Boards could prove fruitful. Again, film elicited discussions are more likely to enable board members with no experience of this group, to gain an insight into their lives.

One important aspect of film-elicited discussion is the space it provides for exploring problematic subjects, for example ideas of dependency or discussion of embodied issues. These issues could be about specific specialist needs, such as physiotherapy or more generally to do with staffing levels or time needed for individuals to undertake certain tasks or ideas about meaningful activities. By using film of real individuals engaged in their real

lives, policy makers and commissioners may be more inclined to recognize the distinct needs associated with PIMD.

Families also queried how national policy was monitored locally. They were specifically concerned that statutory guidance had been issued around deaf/blind and autism (ASD) issues by central government, yet many years later there was still no action on this locally. Dedicated representation on the Health and Wellbeing Board, could flag up these concerns and provide guidance on local implementation of the strategies.

The notion of dedicated representation would also engender a better understanding of staff training and development needs and family carer support needs. This knowledge could be enhanced by the use of multimedia profiling methods, using tablet computers and digital cameras.

8.1.2: Staff Training

Family carers raised concerns that were borne out in later focus group discussions with care workers. Many of the workers, especially in the inner London borough, exhibited a fundamental lack of understanding of basic concepts, such as levels of communication ability. Family carers in the outer London borough had similar concerns about domiciliary care agency staff. People with PIMD have complex support needs which generically or inadequately trained staff cannot be expected to understand. There ought to be a requirement for all domiciliary care agencies to demonstrate to LA's they have the necessarily skilled staff, before securing outsourced contracts. Similarly all LA staff working with this demographic ought to be required to have specific training in the area of PIMD. The training, once undertaken, ought to be monitored and evaluated regularly, in order to demonstrate the skills have been embedded in practice. Video Interaction Guidance (Kennedy, et al, 2011) is one method whereby staff may be guided to reflect on video clips of their own positive interactions with service users. This is currently used in work with families and children, but could easily be used with those supporting people with PIMD.

8.1.3: Specialist Health Services

Family carers' concerns about lack of physiotherapy were borne out in a recent analysis of local need. Family carers in both boroughs highlighted the anomaly, whereby those with PIMD who do not attend a specialist day centre, do not have access to specialist physiotherapy services. This is another reason for a dedicated PIMD representative on local Health and Wellbeing Boards.

8.1.4: Intensive Support Units (ISU) / Local bases

Families interviewed believed their sons and daughters benefitted from attending a day centre. They expressed concern that the centres offered less rather than more days attendance. Families who were offered the more informal approaches were not happy with this. They believed their sons and daughters were missing out on specialist inputs such as physiotherapy. Families overall reported a decline in day service provision, a lack of specialist college placements and the unsuitability of many community mainstream activities. The alternative provision was more informal and not always appropriate for those with high support needs.

Local bases could augment the existing specialist services. There is no reason why these spaces could not include, for example, cafes staffed by people with ID. They could be seen as a space, where the whole community could meet, alongside more private areas for those who need the space and quiet to cope. In this way, people with PIMD could be a part of their community as well as having somewhere to access meaningful activities and therapeutic input on the days they did not have ISU provision. The families, who felt they were missing out because the local day centre was over capacity, would benefit greatly from something like this. It could also act as a resource and information centre for family carers and care workers and would be an ideal space for the delivering of new training initiatives.

8.1.5: Specialist residential respite services

Many of the families, particularly in the inner London borough, have not had access to respite for over ten years. There is a need for specialist breaks services that can accommodate the range of support needs people with PIMD have. For some it is the need for adaptations and aids such as hoists and sided beds. For others it is the need for a quiet space with staff who can build relationships of trust over time. Some people with PIMD are perfectly happy to access mainstream holidays, for others this is entirely inappropriate. Since VP vaunted the notion of person centred approaches, this ought to extend to those for whom specialism is the only appropriate route.

8.2 Future Research

One of the concerns that led to this research was the manner in which people with PIMD are not represented specifically within social policy. It is a contention of this thesis that this results in poor or non-existent services. This relatively small-scale study across two diverse London boroughs has confirmed this. Based on these results, it seems appropriate to suggest larger studies. For example, a UK wide mapping of available specialist services for children and adults, could identify areas of need as well as appropriate provision and areas of good practice. The difficulties for this demographic group appear to be their numbers. Since most LA services are commissioned according to local needs and strategic priorities, this usually means the highest numbers. Hence, notwithstanding the fact that this population is growing, those with PIMD are swallowed up in the wide-ranging remit of learning disability. With the newly formed Clinical Commissioning Groups, this seems an apposite opportunity to rectify this, by having their numbers specifically accounted for on local PIMD Registers.

Considering the state of flux for social care provision in the UK, it is understandable that families may appear pessimistic. At the outset of this thesis, the researcher initially visited the outer London specialist day centre. It seemed the families in that borough had much better provision for their sons and daughters. By the end of the research a different picture has emerged. The outer London borough centre, as has been pointed out, is oversubscribed and the families the researcher was finally able to locate, are deeply concerned about the newer informal service being offered. Indeed, currently there are four families in the process of

taking the LA to Judicial Review, as they were not consulted about the massive outsourcing programme currently taking place.

Not all Partnership Boards have a specific sub-group for those with PIMD. The outer London borough does not. As previously suggested, a UK wide mapping exercise to ascertain where there are PIMD specific sub-groups, could be helpful in this respect. These would be a suitable place to disseminate reports on good practice in this particular area. They could also be the focal point for all LA's, in order to provide national statistics and information to the various government departments. This could allay a further situation, whereby documents are published with no information on those with PIMD. As noted this occurred with the DWP's report 'Improving the Life Chances of Disabled People' in 2005 and the follow up 'Fulfilling Potential,' in 2013.

The focus group discussions with formal care workers produced an abundance of rich data. This highlights the need for more in depth analysis to understand the issues and difficulties associated with providing care and support to people with PIMD. The issues are not easily covered by a one-size-fits-all approach and this needs to be robustly acknowledged. The discussions further demonstrated that workers are rarely engaged in any type of reflective practice. This suggests research ought to be conducted to ascertain why, for example, current training appears to result in surface change but not structural.

Nor has there been a recent study with workers who support this population investigating the defensive manoeuvres Simpson and Miller (2004) discuss. Whilst Sinason (2010) has explored these concepts with ID clients, an analytic investigation into support staff perception and understanding of their role and their own representations of persons with disabilities and with PIMD in particular could only enhance practice.

The family carers' and careworkers' paramount concern that policy makers and commissioners don't get it, resonated throughout this study. The question of how to raise awareness is key. The disability research field has evolved considerably, especially in the area of participatory/inclusive research. However, as demonstrated, this has proved problematic for a discussion of PIMD issues. It is this researcher's sincere belief that the debate is vitally necessary, even if it is difficult. Whilst researchers such as Kittay (in Carlson, 2010) and Carlson (2010) have attempted to open this debate in recent years in the moral philosophical arena, no one has explored the subject in the triangulated method presented here. And no one has found as meaningful a manner, for including an individual

with PIMD in the methodology itself. The unique use of film elicitation has demonstrated the value and possibilities for enabling discussions, which can lead to a deeper understanding of the impact of policy directives on those individuals with PIMD.

8.3 Concluding remarks

There is currently much public discussion about our ageing population and concerns about how we as a society will support our parents and grandparents to have the best possible care in their final years. We have to confront issues of dependency, which may accompany our longer life expectancy. Unfortunately we are failing to acknowledge the lifelong dependent status of people with PIMD. Acknowledging human diversity by recognising value and worth in all relationships, including dependent, can only lead to greater acceptance and understanding of the issues. If nothing else, we must at least start the conversation.

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Appendix A: Participant Information Sheet and Consent Form

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve.

Pease take some time to read the following information carefully and discuss it with others if you wish.

Please ask me if there is anything that is not clear or if you would like more information

Take time to decide whether or not you wish to take part.

Thank you for reading this.

BACKGROUND

When Valuing People was introduced in 2001, it was described as a 'new strategy for learning disability'.

This new way of thinking was called the 'social model' approach.

The idea was not to focus on individuals' specific disability, but on ways to enable those individuals to lead inclusive lives, within their community.

To do this, they would be offered more choices about how they lived their lives.

They would achieve these rights via new improved advocacy services.

In the end it meant these people would be leading more independent lives.

AIM OF THIS STUDY

There has been some concern about how people with 'PMLD' are included in this new approach.

Therefore, this study is to be informed by Focus group discussions and interviews with family carers and paid care-workers.

The research will use short, filmed interactions with an individual with PMLD in order to prompt and guide these discussions.

This part of the study is expected to be completed by the end of 2010.

You have been selected for this study as you are a parent / care-worker of an adult with PMLD.

The study needs the views and input of as many people as possible and initially aims to Interview 10 family carers and hold at least 2 focus group discussions with 10 people in each.

It is up to you if you decide to take part or not. If you do decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

If you take part in a focus group discussion, it is anticipated the discussion will last approx. 45 minutes..

You will be in a group of approx 10 people, either other family carers or your co care workers.

The focus group discussion will include short-filmed sequences, which we will look at and then discuss.

Individual interviews will cover the same areas and will be an opportunity for people to share their insights into the lives of the people they care for.

The interviews will last approx 40 minutes each.

This study has been prompted by the lack of published literature, which specifically looks at the lives of people with PMLD.

It is an attempt to gain a fuller understanding of the needs of people with PMLD, which is why your input will be much appreciated.

All information that is collected during the course of this study will be strictly confidential. Any reference to any individual will be anonymised .

The results of this research will be published as part of a PhD thesis, which will be completed by 2014.

Middlesex University, School of Health and Social Sciences Academic Group and Ethics sub-Committee have approved this study.

Thank you for taking the time to read this / taking part in this study

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Appendix B: Interview Schedule

Q1 What can you tell me about Valuing People? What does it mean to you? For your son/daughter/SU?

'to achieve our goal, where everyone is valued and has the chance to play their full part'

What do you think Tony Blair meant by this, in his foreword to Valuing People?

Q2 VP talks about 'choice' over who provides care and support? How would your son/daughter/SU exercise this choice?Have you been offered a choice of service or support worker, on their behalf ?

Q3 VP proposes new opportunities, to live full and independent lives in the community… can you give me eg's of how this has been achieved with your son/daughter ? day centre accessing the community? Where? How? With whom? Any eg's of other 'new opportunities'?

Q4 Definitions Why do you think VP only uses the terms SLD?

Q5 What do you understand by term 'complex' needs ?

Q6 CB Definition? Firstly, do people know the formal definition for CB and further how have services changed for those who present behaviours, which fall within this definition? How are they different to previous services?

Q7Advocacy? What do you understand by this? Does your daughter/son/SU have one ?How would they access /? How would we know ? IMCA Mental Capacity Act ?

Q8 Community & Equipment services … does she/he/ use any? Have they improved, in what way ? Delivery or actual equipment?

Q9 How different with PCP, what do you understand by PCP, does she have a Plan, a Profile, a circle of support ? Any mention at the DC ? Any different since PCP ? Communication Passport, HAPlan, MultiMedia Profiling? Health facilitator ?

Q10 Have you noticed any change in support, since new training initiatives ? Anyone mentioned to you or had a different approach or more in depth understanding of your son/daughter /SU

APPENDIX C: London Boroughs' Comparative Features

	Inner LONDON	Outer LONDON
Carers Forum	yes	yes
P'ship Board	yes, although future doubtful	yes
PMLD subgroup	yes	no
LD Parliament	no	yes
Residential respite	no	yes
Advocacy	no	no
Specialist Health services	Limited/waiting list	limited
Living with family	36	Est.* 40
Out of borough, resident	34	Est.* 44
In borough resident	11	Est.* 40

* Estimates from LA's JSP

Appendix D: Family Carers

Table 3

Carer IL	Gender	Marital Status	Nationality	Age	Employment	HO	SH	DP	SDC	IS	Res	SC	RH	Ph
HN parent	F	M	WB	40+	PT	X	√	X	X	√	X	√	X	X
NX parent	F	M	WB	70+	R	√	X	X	X	X	X	X	√	√
DX parent	M	M	WB	80+	R									
TD parent	M	M	AC	80+	R	√	X	X	√	X	X	X	X	X
UF parent	F	M	WB	40+	NW	X	√	X	√	X	X	X	X	X
SF parent	M	M	WB	50+	PT									
EP parent	M	M	WB	80+	R	√	X	√	X	√	√	X	X	X
GH parent	F	S	WB	70+	NW	X	√	X	X	X	X	X	√	X
WG sibling	M	S	G	50+	PT	X	√	X	√	X	X	X	X	X

Carer OL	Gender	Marital Status	Nationality	Age	Employment	HO	SH	DP	SDC	IS	Res	SC	RH	Ph
KX	F	S	WB	40+	PT	X	√	X	X	√	√	X	X	X
BL	F	D	GC	70+	NW	X	√	X	√	X	X	X	√	√
NN	F	S	GC	60+	NW	X	√	X	X	√	√	X	X	√
SB	F	S	WB	60+	NW	X	√	X	X	√	X	X	X	X
ND	F	M	GC	50+	NW	X	√	X	X	√	√	X	X	X
TW	F	W	BA	80+	NW	X	√	X	X	√	X	X	X	X

Carer Inner **L**ondon, **O**uter **L**ondon, **F**emale / **M**ale, **M**arried, **S**ingle, **D**ivorced, **W**idow, **S**ibling,

Nationality **W**hite **B**ritish, **G**reek **C**ypriot, **G**reek, **B**ritish **A**sian, **A**frican **C**aribbean

Employment status, **P**art **T**ime, **R**etired, **N**ever **W**orked

Home **O**wner / **S**ocial **H**ousing

Direct **P**ayments

Specialist **D**ay **C**entre

Informal **S**upport

Respite

Specialist **C**ollege

Residential **H**ome / **Ph**ysiotherapy

Appendix E: Day Centre Staff

Day Centres	Female	Male	Nationality	SupportWork experience <5yrs	>10 yrs	PMLD specific
Outer London (OL)	6	5	A x 3 AC x 1 E E x 1 WB x 5 BA x 1	8	3	Yes
Inner London (IL1)	8	1	AC x 6 WB x 3	12	2	No, but majority of SU's
Inner London (IL2)	13	1	A x 1 AC x 7 EE x 1 WB x 5	7	2	Yes

Key: A:African, AC:African/Caribbean, EE:Eastern European, WB:White British, BA:British Asian

Appendix F: ETHICS APPROVAL

Undergraduate and postgraduate students being supervised across subject areas (e.g. CRM and PSY) MUST obtain the agreement of BOTH supervisors.

Staff / Research students / other student applications referred to Social Sciences Academic Group Ethics Subcommittee (SSAGES)

Passed by Social Sciences Academic Group Ethics Subcommittee

Name of 1st SSAGES representative (please print):

Signature: _a lyowna_   Date: 27/10/09

Name of 2nd SSAGES representative (please print): S-Bradshaw

Signature: S. Bradshaw   Date: 27/10/09