

The Authenticity of Person Centred Planning for People who use Learning Disability Services.

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ABSTRACT

This thesis describes an interpretative, qualitative study of one person centred planning, circle of support. The eight people in the circle support a person with a learning disability, to help plan the life the person would like, utilising person centred planning techniques and tools.

This study uses an ontological foundation of phenomenology, existentialism, and social psychology to examine the authenticity of the process of person centred planning for the circle of support members, and the person they have all chosen to support (focused person). A variety of data collection methods are employed, particularly those utilising ethnographic characteristics, and participatory approaches. These include video of a circle of support meeting, informal interviews using a video elicitation technique with circle members, and the use of photographs of the person's plan. The data analysis is interpretative, and uses a two stage thematic analysis. Findings focus on the key concepts of individual agency, social inclusion, rights, choice and social emancipation. In addition the study attempts to examine the individual's "truth" of current service experiences, and of person centred planning as a method of life planning, for people with learning disabilities.

This study adds to understandings of learning disability, and disability generally, by providing new insights into how people should be supported in the future. It emphasises recognising the importance of individual experience both as participants in circles of support, but also as people involved in, or using learning disability services in the United Kingdom. This includes appreciating that human experience is shaped not only by what can be observed and measured, but that

individual agency, imagination, feelings and thought are just as important in how individuals view and experience their world.

List of contents.

Title	Page
Abstract	2
Introduction	8
Chapter 1 Literature Review	15
Part 1 Introduction to learning disability	17
Numbers of people involved	20
Learning disability services	22
Defining authenticity	29
An existential view of “being in the world”	31
Part 2 Concepts of personhood	39
A consideration of why personhood is precluded	41
The medical model and the professionals gaze	45
The theoretical foundations of human thought and behaviour	52
Professional discourses related to personhood	59
Part 3 Person centred planning	66
The policy context	73
The essential principles of person centred planning	81
The personalisation agenda	83
Chapter 2 Methodology	88
Paradigms and research approach	89
Methodological journey	91
Ethnographic approaches	93
Visual ethnography	94
Discourse analysis	97

Visual methods	102
Title	Page
Keith's person centred planning graphics	103
Video of circle meeting	104
Video elicitation	105
The circle of support and initial procedures	106
Group composition	108
Video elicitation clips	111
Video elicitation interviews	112
Ethical considerations	115
Ethics committees	122
Data analysis	124
Chapter 3 Findings and discussion	133
Person centred planning documentary data	133
Relationship map	137
Interview data	138
Primary themes	138
Secondary theme	139
Discussion	140
Person centred planning principles	141
Relationships	147
Personal qualities	154
Positive support	162
Control	165
Inclusion	171

Choice	177
Conceptual model	178
Ethical practice	183
Authenticity in person centred planning	188
Nominal authenticity	192
Expressive authenticity	197
A view of one's self	200
Other individual views of self	205
Instrumental authenticity	209
Chapter 4 Conclusions	218
Strengths and limitations of this study	218
Theoretical and methodological contributions of this study	220
Areas for future research	227
Concluding comments	229
References	233
Appendix 1. Keith's biography	256
Appendix 2. Information sheet	259
Appendix 3. Consent forms	262
Appendix 4. Rules for meetings	266
Appendix 5. Keith's person centred planning graphics	270
Appendix 6. University and NHS ethics approval forms	274
Appendix 7. Interview transcriptions and self instructions	283
Appendix 8. Conceptual model	300
Appendix 9. Thematic development	301

Title	Page
Figure 1. Personal Vs organisational needs	69
Figure 2. Relationship map or doughnut	72
Table 1. The members of Keith's circle	109
Figure 3. Participant and camera positions for circle meeting	110
Figure 4. National Health Service I.R.A.S. Form.	123
Figure 5. Flow chart for study	126
Table 2. Thematic development extract (circle transcript)	128
Figure 6. Thematic development (pre-existing and primary themes)	129
Figure 7. Developing conceptual model	130
Table 3. Research Sequence	132
Table 4. Thematic development (PCP graphics)	135
Table 5. Keith's relationship map data.	137
Table 6. Thematic development across all data types	140
Figure 8. Relationships thematic	148
Figure 9. Personal qualities thematic	154
Figure 10. Positive support thematic	162
Figure 11. Control thematic	166
Figure 12. Inclusion thematic	172
Figure 13. Conceptual model	181
Figure 14. Making Alternative plans process (MAPS)	195

INTRODUCTION

The research described in this thesis focuses on person centred planning, and its use in learning disability services in the United Kingdom. The approach was to define person centred planning and critically appraise the theories and methods that support it, including policies. Also the aim was to design a methodology to investigate its authenticity, and ascertain if as an approach it really does influence quality of life for those that use it.

For this study a single person centred circle of support was recruited, focused on Keith, a single man with a learning disability. A circle of support is an informal group of individuals who come together to help a person plan the life they would like (Burke 2006). They are ideally chosen by the person, and use a number of different, but complementary person centred planning methods and tools to produce a person centred plan for the individual (Sanderson 2000). These will be described in greater detail in part three of the literature review chapter following this introduction.

Briefly, person centred planning as an approach for people with learning disabilities developed in the 1970s and 80s in the United States of America, and Canada. Although it is also used in business to build teams, and provide a vision of the product and/or, service being supplied (Ritchie et al 1993). In the United Kingdom person centred planning came to the fore in the late 1990s following a number of investigations and published reports, where serious failings were found in the way services were being provided for people with learning disabilities (Healthcare Commission 2007). Details of these will be included in the policy section

of the literature review, highlighting those that contributed to major policy changes in the way services were provided in the United Kingdom.

In this thesis I suggest that person centred planning should be viewed in the context of humanistic and existential explanations of how people relate to each other, and their communities (Mount 2000). Rather than operating on a singular field, they operate within a contextual framework that is complex, rhizomatous and explicitly linked with how individuals view themselves, and how others view them (Deleuze and Guattari 2008). The research approach is grounded partly within an existential and metaphysical philosophical framework, these will be fully explored in later chapters, but their inclusion and influence exists on the basis that such explanations begin with the shared belief that there is something particular, purposeful, and special about human beings and the way they think, act, and interact with their world (Sartre 2007). The emphasis on a shared humanity, individual agency and self-determination is thought to be the basis of person centred planning, in addition to acting ethically and in a manner that positively values the person, irrespective of any disabilities they may have (Wolfensberger 1983). The rationale for the study builds on these approaches, and also is based on the belief that people with learning disabilities are entitled to use the same services as anyone else in society, and also have the same equality of rights and freedoms (Wolfensberger 1972; Race 2003).

In any research approach there are inevitably a number of questions and decisions that have to be made, but two important ones regarding the following definitions of ontological and epistemological knowledge, were critical to

underpinning the research approach taken in this thesis. It is also essential to assist in understanding the research question which is, how authentic is person centred planning? Mack (2010) considers the following:-

1. Ontologically: - what is an individual's view of reality and being? In this case it relates to what constitutes social reality for people involved in person centred planning.
2. Epistemologically:- what is known about social reality? What is accepted as knowledge and evidence?

In fact many authors have differing definitions of both, and in some cases use both interchangeably, leading to a very confusing picture (De Rose 2005).

The use of modal knowledge is also significant. This is concerned with objective relationships. Only by focusing on what factors are important and related to producing a person centred plan, can we deduce any relationships. By that I mean how one factor relates to another, how it is connected, how is it produced, and what is essential and necessary and what is not. Vaidya (2010) outlines also the need to consider "essence". Not everything in the world can be accounted for as a result of objectified knowledge. Knowledge produced as a result of modal knowledge, should include the ability of human beings to use their imagination. These generate hypothesis related to what constitutes the "truth", about a particular body of knowledge. These interpretations provide assumptions of what constitutes "truth" within the research design (Clarke 1998) and also provide a focus for developing the research question.

It is also important to recognise how a researcher's views change as a result of the research process. Certainly in my own case, the original proposal differed considerably from the one used in this study. This is also suggested to be applicable in person centred planning. People must be open to new ways of achieving the life the person aspires to, and often innovative ways of working and creative solutions have to be found (O'Brien and O'Brien 2002). This also includes honestly sharing with the person you are planning with, since giving a little of yourself and getting an individual voice into a plan, is thought to be an integral part of person centred planning (Cole and Lloyd 2005).

WHY WAS THIS STUDY CHOSEN?

At the time of the initial proposal I had been working as a learning disability nurse in the NHS in a role which required a person centred approach in order to develop learning disability services within National policy and guidelines (Department of Health 2001). Person centred planning had been studied as my Masters degree dissertation, and I thought combining the two would result in an interesting research study.

I had received, and been involved in training for person centred planning both locally and nationally. As a result of this work a belief developed that only by focussing on a person's individual needs, their aspirations, wishes, and dreams, would people with learning disabilities be enabled to become fully integrated within their local communities, and lead lives as fully participating citizens. I had also met and worked with a number of self-advocates, who also fully embraced this view. One of those people was Keith. Together we worked as service co-trainers learning

from each other, and presented internationally in Hawaii, all as a result of person centred planning. Keith's biography is included as **Appendix 1** of this thesis. Towards the end of this study I retired from the National Health Service, but continued to support Keith as a friend and a member of his circle of support.

I have changed his name to preserve confidentiality; he agreed to participate on the understanding that highly personal information was not shared. Some authors suggest that personal narrative accounts provide a more authentic description of both the individual, and the challenges they face in living their life. The following brief outline is included, which we compiled together (Walmsley 2001; Goodley and Tregaskis 2006),

Keith is a middle aged man with a mild learning disability. His I.Q was tested as 69, and although his verbal communication is excellent, he has difficulties in understanding what people say, particularly if they use complex words or phrases. He also has cerebral palsy, which has left him with a weakness down one side of his body. As a result he has difficulties with walking, standing for long periods, fine motor co-ordination and balancing. He occasionally falls over, particularly if walking on uneven, or surfaces that change (e.g. from carpet to tiled flooring). He requires personal assistance with all care, and activities required for daily living. He has a hearing impairment, and visual difficulties. However, he can read large print. He has no sense of direction, so is unable to find his way around outside his home unaided. He lived at home with his parents for many years, but during this study moved out into his own flat in a sheltered living facility for older people. He enjoys reading especially modern history and biographies, watching sport on television, going out with friends and family, and taking part in quizzes.

THESIS CONTENTS AND DESCRIPTION

This thesis begins with Chapter 1 a review of literature related to the field of study. It also introduces some new literature relevant to the field of learning disability research. It is divided into three parts:

Part 1 introduces learning disability and learning disability services. It defines authenticity, and discusses existential philosophical thought relating both to supporting people with learning disabilities.

Part 2 examines concepts of personhood including emancipatory epistemes and social presence. It includes a consideration of why individuals are precluded from personhood. The medical model of disability is discussed and contrasted with the social model of disability. There is a discussion of professional discourses and how they are related to personhood.

Part 3 is dedicated to person centred planning. It describes its basic requirements and discusses why it offers as an approach, an alternative form of life planning. The policy context is described as it applies to people with learning disabilities in the United Kingdom, but with particular reference to person centred planning. The ontological foundations of person centred planning are examined within the context of defining the essential principles of person centred planning.

Chapter 2 is the methodology chapter for this study. It describes the paradigms used and the research approach. This includes a discussion of the methodological journey taken, and the final approaches used. It also describes data

collection, data analysis and ethical considerations important for this study. This includes applying to ethics committees and a personal reflection of this process. It also describes the process of developing a conceptual model from the research findings.

Chapter 3 is dedicated to discussing the research findings in detail, relating them to the research question, and theoretical positions taken. It also includes a discussion of the conceptual model, and its individual thematic components.

Chapter 4 is the conclusion of this study. The contributions of the study are considered, including any perceived limitations. Areas for future research are also suggested, and the chapter concludes with a summing up of this study.

LITERATURE REVIEW CHAPTER 1

PART 1

INTRODUCTION

The majority of this section relates directly to person centred planning and learning disability services in the United Kingdom. However, in order to answer the research question related to how authentic it is as an approach, a section on authenticity is included. A critical part of defining authenticity relates to individual personhood, and how it is defined and viewed by others. Also importantly how the individual views their own personhood. Personhood and being human are often viewed as interchangeable definitions. It is only perhaps philosophers who consider the broader implications of what it means to be human, and how personhood is ascribed. The various explanations on the subject, which relate to known bodies of knowledge, indicate that there are individual and state duties involved (Goertz and Mahony 2012). These relate to rationality, acting ethically, and within society's legal and moral frameworks (Cocchiarella 1996). There are also theological frameworks which govern how an individual is expected to behave. Also in what situations and contexts for example, the noble eightfold path guiding human behaviour and leading to Nirvana in Buddhism (Trainor 2004).

Many individuals intuitively recognise they are a person and a human being because of their assimilated "a priori" knowledge. In this case "a priori" refers to the Kantian definition where such knowledge is transcendental, and is based on the form of all possible experience (Foucault 2008). However, it is also interesting to note that there are people who are often not recognised as persons and this needs further

explanation if one wishes to understand personhood (Laitinen 2002). There will not be a lengthy discourse in relation to bioethics or the treatment of animals, particularly cetaceans or the great apes, as the main discourse is concerned with humanity and personhood. However, there is a critique related to specialism and the universality of human rights which needs to be acknowledged (Cushing 2003). This impacts directly on episteme's related to non-persons, and how and why individuals negate their behaviour to those perceived in this domain.

The question of personhood is particularly related to my research interest in person centred planning, and how this affects my professional practice. It is difficult to plan with a person if it is not possible to clarify if that individual is accorded personhood. Indeed the whole tenant of person centred planning is based on promoting individual autonomy, and should enable individual empowerment and life aspirations. In order to achieve this I suggest that personhood is fully accorded to all participants in person centred planning. Some authors also support this view considering that recognising personhood for people with learning disabilities, and those that support them, is an essential component for any support or assistance they receive (Dearden-Philips and Fountain 2005; Thompson, Kilbane et al. 2008). There are unfortunately many examples where people with learning disabilities have not been seen as people in their own right, and as a result have been treated in abusive ways (Healthcare Commission 2007).

I have included some epistemological explanations which examine discourses related to the role of professionals, including the medical model of service provision, philosophical explanations of personhood (related to scientific rationality and

metaphysical enquiry), and legal/ethical considerations (related to justice, autonomy, social inclusion and self determination). However, I would first like to consider people with learning disabilities, and the services they use.

INTRODUCTION TO LEARNING DISABILITY

Before considering learning disability services in detail, I would like to provide a brief introduction to learning disability, and the terminology used in the United Kingdom. This is important since it reflects the emancipatory discourses that provide the basis for this thesis. Indeed personhood and how individuals are accorded that status is reflected in what terminology is used to describe people. In general people with learning disabilities are treated as different by society, and do not have the same control over their lives as the rest of society.

This means that for most individuals discrimination and prejudice are challenges faced on a daily basis. At least half of all adults with a learning disability live in the family home thus restricting the chance for independence. Of these 29,000 adults live with parents aged 70 or over. Many of these are too frail to continue caring, and only 1 in 4 have alternative housing planned by the local authority (MENCAP 2012).

In the United Kingdom learning disability was adopted as a term in 1991. It was a welcome replacement for other terminology, for example mental handicap, mental deficiency or mental retardation, still in use by some countries internationally. Learning difficulties is still used in educational services. This provides a broader definition and includes individuals with difficulties in learning for example dyslexia,

those with autistic spectrum disorders (autism and Asperger's syndrome), and those with behaviours that challenge others (Goswami 2008). This term is also used by a number of local authorities, and self-advocacy groups as their chosen terminology. Increasingly on an international level there is a call for intellectual disability to be used (Mansell and Beadle- Brown 2004). In this thesis the term learning disability is used because that is the term Keith prefers. However, he really would like people to relate to him as Keith. He states:

“I am Keith a person not a client, patient, guest or service user I am just me”.

This view is also shared by other authors critical of the medicalisation of people who use services, and mindful that whatever service is used the “person” is often lost amid a plethora of interventions, professional assessments, risk assessments and service requirements (Speraw 2009) . The treatment of the person as “object”, rather than a fellow human being has been described aptly by Goodley Lawthom et al (2004).

However, irrespective of the term chosen people with learning disabilities face the following life challenges present from birth or shortly after. All face intellectual challenges that cause difficulty with understanding new or complex information, learning new skills, and managing to live independently. Commonly these will include difficulties with understanding and using information, problems with making choices and decision-making, coping with social situations, and reading and writing (Department of Health 2001). Many people with a more severe learning disability will use alternative forms of communication for example pictures, symbols or specialist communication aids and systems. Although the degree of learning disability can vary

from mild to severe, the greater the degree, the greater the individual persons need will be for help and support (Poncelas and Murphy 2007). Some people with more complex needs will also have additional difficulties for example physical impairments, sensory impairments, psychological difficulties, mental illness or neurological conditions such as epilepsy, behavioural difficulties and genetic impairments with specific health needs for example Down's syndrome (Department of Health and Department of Education and Skills 2005).

People with learning disabilities often need help with the ordinary activities required for daily living for example, how to live and where, getting about in their community, work, leisure, relationships and staying healthy and fit (Goodley 2000). There are particular health challenges for people with learning disabilities. They are more likely to suffer from cancer, respiratory problems, take less exercise, and have high risk of obesity (Department of Health 1998). Many self- advocacy groups actively promote the themes of choice, rights and freedom to use all the services and privileges, accorded to everyone in society for people with learning disabilities. They emphasise the positive aspects of having a learning disability for example, the RESPECT self advocacy group in the Southwest indicated in a group statement that irrespective of the challenges they face, people with learning disabilities have experiences, thoughts and feelings to share with the world. Most information concentrates on what people cannot do instead of what they can do, and it is suggested this needs to change (RESPECT 2011). These views were endorsed in the Government's Annual Report on Learning Disability commissioned by the Valuing People Team (Valuing People 2005). In particular there was seen to be a need for people with learning disabilities to be involved at all stages of service and

policy development. Most self- advocates and people first organisations signed up to these principles. Self- advocates are people with learning disabilities who advocate for themselves. Many are closely involved with People First which is a national and international organisation for self- advocates. These individual groups promote recognition and social justice, in addition to providing information on a variety of issues commonly faced by people with learning and other disabilities, for example abuse and discrimination (Henderson and Pochin 2001).

The Government issued *Nothing About Us Without Us* to outline these key principles (Department of Health 2001). This was a health service user group report commissioned by the Department of Health. Its key message was that all services should include people with learning disabilities at all stages of service development, but not in a tokenistic way. In this way it was hoped that the needs of people with learning disabilities would be more appropriately met, promoting social inclusion, advocacy and citizenship as a result. Self- advocacy groups were highlighted as one of the key areas to enable the effective implementation, and must receive appropriate funding. It recommended funding from an independent body, through pooled budgets and joint funding initiatives. It was the first time people with learning disabilities had been involved in advising the Government on a strategy, and reporting directly to the Minister for Health.

NUMBERS OF PEOPLE INVOLVED

It has proven to be very difficult to find the actual number of people in the United Kingdom with a learning disability. This is partly because until quite recently individuals were not recorded, and also because the definitions of learning disability

vary greatly. In the White Paper *Valuing People* (2001), it was estimated that the number of people with severe and profound learning disabilities in the population was 210,000. The estimates for those with mild/moderate learning disabilities was 1.2 million, a prevalence rate of 25 per 1000 (Department of Health 2001). It was estimated that in 2008 there were 145,000 people with severe or profound learning disabilities with an estimate of 177,000 known to learning disability services representing 0.47% of the total population. Of particular interest was the predicted increase in the population of people with learning disabilities as a result of a number of factors. Firstly, there was a two to threefold increase in the incidence of people born with a severe learning disability in the Bangladeshi and South Asian minority ethnic communities. Secondly, increased survival rates for young people with severe and complex disabilities, and finally reduced mortality rates for those older people with learning disabilities. This results in a projected 15% increase in numbers across the decade 2001-2011, and a projected 20% increase over the next twenty years 2001-2021 (Emerson and Hatton 2008).

It would appear that services will have to prepare themselves in future for an increase in the numbers of older people, and those with more severe and complex disabilities. Perhaps that is why services are moving from a generic provision of services by learning disability teams, to a more specialised community learning disability team with the focus on health facilitation (providing access to mainstream health services with the aid of a specialised nurse, or other health professionals), and focused individual casework and interventions (Moore and Thorley 2011).

LEARNING DISABILITY SERVICES

Historically people with learning disabilities have been treated in a variety of different ways depending upon the society and cultural norms and values that existed. A variety of different labels have been used to describe them ranging from idiot, imbecile, feeble minded, holy innocent, subhuman, object of ridicule and pity, and eternal child (Wolfensberger 1972). There developed as a result of lack of medical knowledge about people with disabilities generally, two views. The first was one of suspicion and fear. The belief was that people with learning disabilities in particular were a dangerous influence on society and should be prevented from co-existing. As a result at best they were segregated, and at worst killed or persecuted. Secondly, they were thought either to have special or supernatural powers so were either revered, or treated with suspicious curiosity. Wolfensberger (2011) describes the special status accorded to “hombre de placer” in the Spanish Court of King Philip IV. Many of these individuals had learning disabilities and were given particular employed roles in the court, for example, companions to the queen. Similarly, there is a remarkable description of a shrine in Shah Daulah, Pakistan where “chuas” lived. These were people with microcephaly living as a community; the belief was that they must be supported as their well-being was of prime importance to the religious beliefs, and continued welfare of the country (Miles 1996).

The majority of people with learning disabilities continued to be supported within the communities in which they lived. In the United Kingdom state intervention and assistance for their care was introduced in 1353 under the auspices of De Perogativia Regis (Kirman 1975). This legislation required the families or guardians of people with learning disabilities (classified as idiots or natural fools), and people

with mental health problems (classified as lunatics) to protect the lands from their negative influences, and ensure they remained profitable to society. In other words they worked often in very menial occupations, and were excluded from society. This view continued into Elizabethan times when the Poor Act of 1601 was introduced. In order to protect society from their undesirable influences many groups of people were incarcerated in poor houses. These represented the first introduction of institutionalised care for people with learning disabilities.

Views that people who were different from society's expectations of normality, and as a result represented an undesirable threat, persisted into the 18th and 19th centuries. The Industrial Revolution brought with it a demand for skilled, physically fit individuals. People with learning disabilities were considered unprofitable and a burden to society since they lacked many of the skills required. The Poor Law Amendment Act 1834 was introduced to resolve these fears, and many vulnerable people were sent to workhouses (H.M.S.O. 1834). Living conditions and treatment in these were generally unacceptable in comparison with what would be viewed as appropriate today. People were separated into different wings depending on sex, families were split up. Everyone had to work, even children, living conditions were overcrowded. Food was poor and innutritious. The emphasis was on housing and feeding large numbers of people, in the cheapest possible way (Wolfensberger 1975).

During the late 19th and early 20th centuries it was suggested that many of the perceived ills of society for example, prostitution, crime and alcohol dependence, were associated with people with learning disabilities, and other devalued groups. It

was also believed that these people and other undesirable groups for example criminals, the mentally ill and homosexuals, procreated faster than the rest of society. This resulted in their offspring representing a threat to the moral fabric of society, leading to its general collapse. It was also believed that many of these undesirable groups had heredity traits that could be passed on.

This resulted in the development of the Eugenics movement founded by Sir Francis Galton (1882-1911). Galton rejected the theory of natural selection developed by his cousin Charles Darwin. He disputed Darwin's suggestion that in nature only the strongest and fittest survive, and proposed it was only by selective breeding from parents with desirable traits, that any race and ultimately society could be improved (Galton 1883). He advocated breeding from the intellectual classes (positive eugenics), and the prevention of breeding from those deemed socially deviant (negative eugenics). There were many prominent members of society who supported these views for example, Marie Stopes the champion of women's rights, William Beveridge founder of the post war welfare state, and Sir Winston Churchill statesman, writer and raconteur. Indeed Churchill suggested institutionalising people of weak intellect, and even sterilising them. Thus preventing "idiots" from reproducing, halting the perceived decay of the race (James 2013).

In 1909 a Royal Commission was set up to investigate the problem of "the feeble minded" its recommendation was incarceration in institutions (Woodroffe 1977). In 1913 the Mental Deficiency Act was introduced in the U.K. Its purpose was to build on the recommendations of the Royal Commission and to legalise the detention of people with a variety of mental defects. For this purpose people were classified as idiots, imbeciles, feeble-minded persons or moral defectives. The First

World War (1914-18) largely disrupted its implementation, but the recommendations of the Wood Committee resulted in an increased acceleration of the policy. Its main recommendation was the formation of self sufficient “colonies” that would house all groups of “mental defective” (Wood Committee 1929).

These campuses tended to be located outside of towns, and were self-contained villages specifically for people with learning disabilities. Far from representing an ideal place to live, such institutions became known for abusive practices, and the mass handling of people where the individual became lost. Indeed many authors described sterile environments devoid of colour and stimulating activities, an “us and them attitude” with regard to the staff and the people living there, and an organisationally dominated existence based on timetables and routines (Goffman 1961; Wolfensberger 1975; Wolfensberger 1984).

In 1946 the NHS Act (H.M. Government 1948) resulted in the word colonies being changed to hospitals, when responsibility of these institutions was transferred to Regional Hospital Boards. Admission was based on the request of the family, a petition of local people, or legal representation from Authorities for example, the police. However, admission had to be sanctioned by two Doctors. There are many examples cited in narrative accounts how individuals were incarcerated, often for the most minor of transgressions. A common theme was a lack of power and control over their day to day existence, having to abide by strict rules and regulations, punishment for infractions which at best resulted in loss of privileges’, and at worse constituted physical, mental or emotional abuse, and an inability to form lasting relationships with family or friends (Barron 1989; Atkinson and Williams 1990).

It comes as no surprise that during the 1960's a number of reports were published questioning the appropriateness of care in institutionalised settings. Probably one of the most widely known was the Report of the Committee of Enquiry into Ely Hospital (Howe Report 1969). It highlighted people living in squalid impoverished conditions, and staff who implemented physical custodial care, and a variety of abusive institutionalised practices. A number of research studies followed, indicating that many individuals living in institutions, had the intellectual and social capacity to live independent lives in the community (Race 1995). The implementation of the Mental Health Act 1959 (H.M. Government 1959) ended the process of compulsory certification for admission, and introduced admission criteria and definitions. As a result this enabled many people with learning disabilities to be discharged from long stay institutions.

The White Paper Better Services for the Mentally Handicapped (Department of Health and Social Security 1971) recommended a 50% reduction in hospital places by 1991, and a significant increase in Local Authority provision for residential and social care. This was followed by the influential report (Jay Committee 1979) which accentuated these views. In addition it highlighted the need for staff retraining, and a service philosophy founded on the principles of normalisation (Wolfensberger 1972). This sought to ensure that people with learning disabilities were supported and encouraged to lead culturally valued lives in the community. It paved the way for a different approach in the provision care for people with a learning disability, and how they lived their lives. It introduced the principles of choice, control, and citizenship. These are viewed today as important requirements for desirable service delivery and support. During this time a number of informal networks arose based

around Programme Analysis of Service Systems(P.A.S.S.) workshops (Wolfensberger and Glenn 1975). This was an American service evaluation tool based on normalisation principles, aimed at developing community based services for people with learning disabilities. These principles were consolidated in the Jay report which recommended services should be based on promoting an “ordinary life” (Jay Committee 1979). It also made a number of recommendations for mental handicap nursing. These were consolidated in the later seminal document “An Ordinary Life” (King's Fund 1980) . During the late 1970's and early 1980's hospital closures continued, based on successful community service programmes developed in Scandinavia, America and Canada. In Denmark many asylums were closed in this period, and local communities took responsibility for the care of people with learning disabilities. The new services were described as “ a sheltered life”. They consisted of local staffed sheltered housing, workshops and arranged leisure activities (Bylov 2006).

The emphasis through normalisation and an ordinary life, brought with it challenges to the previously paternalistic provision of services in the United Kingdom. Although as in Denmark the provision of services still tended to be professionally led, with an emphasis on community based small group homes, day services, short term respite care, or small community based teams provided by a team of suitably qualified professionals(Brown and Smith 1992). The care and support of people with learning disabilities was still viewed as very much a job for professionals. However, people with learning disabilities (particularly those discharged from institutions) were starting to form support groups, and develop their own views on how they wished to be treated by society. In Denmark this took the form of self advocacy by people recently discharged from institutions. These

individuals rejected the passive role of people with learning disabilities using services, to an active role of shaping and transforming services. They started by rejecting professional descriptions used to define people with learning disabilities and developed the term “Udviklingshaemmet” which means developmentally hampered. Using this term was important since it was new, and had never previously been used in any form of legislation. It also enabled individuals to use the term as a way of self definition (Bylov 2006).

A similar development was taking place in the United Kingdom, people were starting to realise they had a choice about decisions relating to how they lived their lives. This was beginning to be supported politically with a move away from state centralisation, and the provision of paternalistic care and treatment services. The emphasis was on unified social services, decentralisation and community care (Race 1999).

The Griffiths report in 1988 further reinforced these views also that people should be involved in decisions related to their care and treatment. It recommended hospital closure and a move towards community based services. These recommendations resulted in 1990 in the White Paper *Community Care in the Next Decade and Beyond*. The main change in the act was a split from local authorities and health authorities. The local authorities purchased services from providers such as the National Health service (NHS) and health authorities. The local authorities became the lead agency for assessing people’s needs, and then purchasing community based services to meet these needs. There was a particular emphasis on involving individuals and their families, and giving them a variety of choices to meet their needs. Some have likened this as a move from welfare consumerism to a move

towards empowerment, since individual choice and control were central to the provision of services (Oliver 1994; Davis 1996).

This purchaser/provider split has remained to this day, and most learning disability services are now provided wholly in the community, by a range of services. These include voluntary and private sector organisations and charities, for example MENCAP, and The Foundation for People with Learning Disabilities. It also includes provision from statutory services, for example the NHS, Educational Services and Adult Social Care. Increasingly, there is a move towards greater personalisation of services and greater choice and control for individuals about the life they wish to have (Department of Health 2009), and these issues are explored in greater depth in the policy section of this chapter.

DEFINING AUTHENTICITY

An individual's view of themselves and how others see them are also important factors which lead to a definition of authenticity. This is a critical question in this particular research thesis, but many authors struggle to effectively define what authenticity means.

Handler (1986) considers that authenticity is a cultural construct of the Western world. It relates to an authentic cultural experience and concerns itself with cultures that are untouched, unspoiled, pristine, genuine and traditional. It is also very closely connected with the individual and how that person interacts with the world as a whole, and their own individual world. Authenticity is an expression of the individuals 'true' self, their individual existence. How the person appears to others,

and interacts and relates is also important, but what really matters is their own individual internalised view of themselves (Greene 1952). Thus authenticity also represents a truth as it appears to the individual, and as a result leads to questions regarding the various beliefs that are important for the individual (Van de Port 2004). In this context it is very relevant to the act of person centred planning, since the whole purpose is to help the individual attain the life they aspire to, or at least go some of the way to achieving that goal.

Some authors view authenticity purely in terms of a moral concept, for example, Sartre considered any “act of bad faith” inauthentic since the individual was negating to make choices which ultimately affect their life, or their position as a being in the world (Jackson 2005). It would also be the case that authenticity can act as a descriptive and critical concept, for example a work of art can be a forgery and described as such, because it lacks certain critical descriptive values related to a particular artist (Baugh 1988). Person centred planning can therefore, as a concept be determined both in terms of descriptive and moral authenticity because of the presence (or absence), of certain qualities and values, and their relationship to the goals and aspirations of the valued person. Authenticity is discussed in greater detail in Chapter 3, the findings and discussion section. It includes an analysis of authenticity and how it relates to person centred planning in this particular circle of support.

Sartre also viewed authenticity in terms of the individual’s interaction with their environment and world. This occurred both on a conscious and unconscious level fulfilling their own destiny. His view of authenticity is related directly to authentic

being. He argued that all human beings come into the world as a blank sheet, and must make of themselves what they will. In other words, individual self-determination is the direct consequence of the individuals conscious or unconscious actions and interactions (Johnstone 1980; Bell 1989).

The idea that each thing is authentic because it exists not only on its own, but also in relation to the world is a central tenet of existential thought and philosophical writing.

AN EXISTENTIAL VIEW OF “BEING IN THE WORLD”

Existentialism is essentially definable as how we exist as human beings. It concerns itself with questions related to ‘being in the world’, and offers an alternative explanation for the meaning of human existence (Marino 2004). This can be ‘being’ on an individual level, for example questions relating to: - Why do I exist? What is the purpose of my life? What do I make of being in the world, and How do others view me? Or it can be on a broader episteme for example: - Why does humanity exist? What is commonly believed by humanity?

The whole tenet of learning disability service provision including person centred planning, is based on egalitarian principles of social inclusion, civil and moral equity, and a shared common humanity. This is aptly illustrated in the paradigm of person centred counselling, based on the core principles of empathy, unconditional positive regard, and genuineness or authenticity (Woolfe 1996). In order to empathise one must be able to view the world from the point of view of another. This is often the case when supporting people with learning disabilities, particularly those people unable to advocate for themselves, or those with complex disabilities that

prevent social communication (McIntosh and Whittaker 2000). It is closely related to unconditional positive regard which involves a non-judgemental acceptance of the person, valuing them for who they are (Bell 1989). Finally, genuineness or authenticity, which requires people to be honest and open, particularly when communicating feelings, thoughts and advice to each other (Rogers 1951).

Jean Paul Sartre encapsulated these principles when he described his view of existentialism which he also considered a humanism:

“When we say that man chooses himself, not only do we mean that each of us must choose himself, but also that in choosing himself, he is choosing for all men”.

Existentialism is a Humanism (Sartre 2007) pg 24.

So in thinking for myself, I also think for other people, (including people with learning disabilities). In acting in a particular way I also act for other people (Sartre 2006). It is a fact that Sartre used what would be considered today very sexist language (Bell 1989). In the context of this study when quoting Sartre I have modified the language to include all sexual orientations, and prefer the use of person or people rather than any specific group (unless quoting Sartre directly).

This authentic grounding, the effort expended by the individual to act in the world is important, but equally relevant is what resources individuals utilise in order to act, to believe, and take things to be true (Van de Port 2004). There are far too many different existential explanations centred on being, and being in the world to

include them all. I will therefore concentrate on two authors who I feel support the assumptions relevant to person centred planning, but offer different explanations. Although distinct and separate they can, when taken together give a greater insight into man's existence. These authors are, Jean Paul Sartre and Emmanuel Levinas.

Jean Paul Sartre's existentialism focuses very clearly on people and their individual place in the world. He makes a very clear distinction between humans and other objects in the world. To Sartre a human represents a being-for-itself. This means that an individual is able to consider their position in the world, and consciously think about themselves as separate from other objects which are described as beings-in-themselves. He builds on the work of Husserl and later Heidegger, viewing that a human's natural attitude is to experience the world as it appears to us as individuals (Sanchez 2007). Religious beliefs and scientific rationalism offer different interpretations on how people make sense of our world. Religion focuses on the belief that our perceptions of the world are shaped by a higher other worldly being. Science perceives the world in terms of proven facts or fundamental laws. Here objects that are often taken for granted in our everyday life are given the meaning to exist as themselves (beings-in-themselves) in essence, in consciousness, or in our unconscious thoughts transcendently.

This ability to reflect on the world, freed from preconceptions is thought to be critical to the understanding of person centred planning. Without the ability to think creatively, unhindered by our own individual biased view of the world, it is suggested effective person centred planning will not take place (Forest, Pearpoint et al. 2003). Often people with learning disabilities are precluded from any consideration of this

kind of thinking because of the nature of their learning disability, and the way they are viewed and classified often by professionals and services. People are seen in a deficit dependant classification based on impairments, and subject to the decisions of others either to keep them safe, or to keep others in society safe from them (Department of Health 2005). This tension between people with learning disabilities being afforded the full rights of citizenship on the one hand, or being treated within a paradigm of lifelong dependency and vulnerability, is particularly relevant to the consideration of the authenticity of person centred planning (Redley and Weinberg 2007). It is also relevant in any discussion relating to how people reflect on the world in an existential manner. Indeed there are many examples of people with learning disabilities reflecting and recalling how they have experienced the world in creative narrative accounts, unbiased and free from preconceptions that support this view (Espiner and Hartnett 2011).

Sartre drew heavily on the work of Heidegger, particularly his view of being-in-the-world. Heidegger used this way of thinking about how humans experience the world to introduce the concept of Dasein which means life, presence or existence (Heidegger 2008). The 'thereness' of being as a human, is linked very clearly with existence and being in the world. We experience the world as it is, but we are also intimately linked with it transcendently, in our conscious and unconscious thought processes. Heidegger views Dasein as part of the human condition, much of what it means to be Dasein is transcendental, and hidden from our public gaze. There is also the conscious part of being where we as humans have a public face and act in a public way, this is the "they self" or public side of Dasein. Often this results in greed, idleness, judgemental comments and actions. In fact the part of

being human that is less attractive, and in some cases illegal, immoral, and even inhuman (Moran 2002). Sartre used this approach to develop his concept of acting in bad faith which will be considered later on in this chapter.

Sartre departs from Heidegger's description of consciousness in the following way. If one considers humans as thoughtfully aware of their position in the world as separate from other objects, consciousness represents the space or emptiness that separates them from beings-in-themselves (Sartre 2008). Sartre develops the idea of nothingness which occupies space, it is outside the conscious person, but it also exists inside the person representing the emptiness within. The individual seeks to fill this internal nothingness with his own thoughts, wishes and actions. It is the emptiness within that enables the human being to both perceive and act within the world. It also distinguishes the individual from objects or beings for themselves which are solid, immovable, and unlike the human unable to act upon the world they simply exist. Sartre draws on the work of Hegel (1975) who uses the analogy of a building to describe his concept of metaphysical thought. Although it displays the spirit of the person who created it in its mass, the image of the creator is not displayed there. In Sartrean terms the building just exists it represents a being-in-itself. Whilst its creator represents a being-for-itself, with an untapped potential to change themselves, and the world in which they exist.

There are some similarities in this description with regard to person centred planning and supporting people with learning disabilities generally. Both consider and value the individual person with learning disabilities. Person centred planners talk of qualities, strengths and gifts (Snow 1993). Services refer to positive strengths

needs and goals (Robinson and Chenoweth 2011). Both aim to increase the potentiality of the person to enable them to achieve “an ordinary life “.

Jean Paul Sartre defines his existentialism as atheistic existentialism since he does not believe in an other worldly god, producing and shaping human nature. To Sartre there is a simple explanation of existentialism in that people have a human nature (essence). This is common to all but it is different from a god given human nature (Sartre 2007). In humans, existence precedes individual essence, in that a person is born into the world as nothing, rather like with a blank sheet of paper. The script is yet to be written. A person is a being who exists, before he or she can be defined by any concept of what it is to be human. The individual then interacts with the world, and as a result of this defines him/herself, or essence. Sartre states:

“if a man as existentialists conceive of him cannot be defined, it is because to begin with he is nothing. He will not be anything until later on, and then he will be what he makes of himself”.

Existentialism is Humanism, Sartre (2007) pg 22.

Sartre believed that human destiny was the result of an individual’s own actions. He firmly believed in the Cartesian principle of “Cogito”, I think therefore I am (Sartre 2004). He also believed that humans were unique and distinct from just being an object in the world, or an animal similar to other animals. There is a set of values distinct to being human which shape our actions. The “I think” part of the cogito defines not only the individual’s self, but also what it is like to be human (Sartre 2007). Sartre believed that there was no universal human nature, but it all

depended on the person and how they went about their life. Life is nothing until it is lived, there is no “a priori” human existence, it is defined as we all go through life both individually and collectively. If an individual is responsible for making him/herself, then the individual is also responsible for acts of bad judgement or bad faith.

Sartre defined authenticity in terms of individual existence. He viewed the individual as capable of authentic existence, only by making every attempt to achieve the maximum potentialities as a person. For Sartre being a human and existentialism were closely connected. To be human relied on a degree of self determination, and recognition that every person was an individual in the making. Existentialism should be non-judgemental. It promotes an ethical consideration of human actions, and importantly, a belief that everyone can have dreams and aspirations. These are important for shaping our lives both individual and collectively. There are indeed many analogies here with regard to person centred planning (Mount 2002) and the ethical stance advocated by Emmanuel Levinas, whose work will now be considered.

Levinas was responsible for developing ethical metaphysics. Levinas uses the work of both Husserl and Heidegger to produce a philosophy which concentrates on the moral superiority of the other person (Levinas 2001). For Levinas acting in an ethical way for the benefit of others takes precedence over any form of action for oneself. The taking responsibility for others is a transcendental thought but is translated into direct and indirect action on the part of the person (Levinas 2003). This highly moral and ethical responsibility is the centre of Levinas’s philosophy, and in particular he proposes the moral responsibility for others is a

central part of human existence. He is therefore very critical of Heidegger's Dasein, and Sartre's "being for beings sake". The humanity of man and in particular its response to the vulnerability and suffering of others, is a key part of human existence. Levinas also thought that man does not constantly think about his own death, but rather goes through life acting in a moral way to relieve suffering in others, and leave the world in an improved state for future generations. It must also be recognised that Levinas was very religious and particularly (being Jewish himself), objected to the Nazi treatment of the Jews in the Second World War, and the fact that Heidegger was a member of the Nazi party. Levinas remained an enthusiastic critic of Heidegger all his life (Appignanesi 2006).

Levinas's ethical moral philosophy particularly the promotion of empathy, through recognising the vulnerability and suffering of others, is a key requirement for any form of person centred planning (Mount 2002). Planners are always encouraged to be positive, look for qualities and gifts in individuals, and at all times promote the view of equality, inclusion, and positive regard. It is also important to recognise that all individuals are unique. They all have the ability to make their own particular contributions to society. Irrespective of what particular difficulties or labels they have as people, for example challenging behaviour, autistic spectrum disorder, or learning disability (Mount 2000).

However a fundamental question related to person centred planning is the notion of personhood and how individuals are accorded the status of person, both in terms of individual autonomy and personal agency, and how the individual accepts personal responsibility. Also how others accord them the status of valued person

(Foucault 2008). This acts in opposition to a widespread discourse that seeks to de-humanise and devalue people with learning disabilities. As evidenced in the treatment of people with learning disabilities whilst being treated in an acute hospital setting. Care without dignity, respect or any regard that the person is a fellow human being. In fact what has been described as institutional healthcare (MENCAP 2007) .

These issues will be explored in the following sections of this chapter in greater detail. Also discourses related to social presence, non- personhood, learning disability nursing, and the medical model of health service provision will be examined.

SECTION 2

CONCEPTS OF PERSONHOOD

SOCIAL PRESENCE AND EMANCIPATORY EPISTEMES

The concept of social presence appears to be a fundamental principle in attempting to define personhood. In the field of learning disability services it arises from the principle of Normalisation and later reworded Social Role Valorisation (Race 1999). This approach or episteme is based on the egalitarian principles of the rights of people with learning disabilities, and the equality expressed in terms of the individuals rights to a quality of life corresponding with any other member of society. Emerson (2001) is critical of the approach considering that it fails to recognise the issue of segregation in service design, but Wolfensberger has refuted this criticism in a number of ways including his description of life in a Nazi concentration camp (Wolfensberger 1984), the emotive descriptions of characteristics of segregated institutions (Wolfensberger 1975), and finally his description of programme analysis

of service systems implementation of normalisation goals (Wolfensberger and Glenn 1975).

The basic aim of any of these approaches is to ensure that people with learning disabilities are supported to develop culturally valued social roles, and avoid them being cast in damaging stigmatising roles. It is also aimed at ensuring they have the same civil and moral rights as the rest of society. This includes rights of access to all the services available to other members of the population. In response to criticism that Normalisation implied an individual was abnormal, deviant or damaged (Nirje 1970; Bank-Mikkelson 1980), Wolfensberger developed Social Role Valorisation (Wolfensberger 1983). For Wolfensberger the most important matter was social integration, he was less worried about the right to individual choice. This approach was heavily criticised by some authors (Nirje 1985) especially with the emphasis on conforming behaviourally to societies expectations. Such an authoritative approach was viewed as an abuse of the power of the therapeutic state.

O'Brien's five accomplishments (Brown and Smith 2001) built on Wolfensberger's work, and aimed to return to basic values, an approach that had become overtly theoretical (O'Brien and O'Brien 2002). Major emphasis is placed on the individual, and their choices both in terms of lifestyle, and quality of life. They emphasise community presence, rather than segregation within their chosen community. Also that individuals are supported to make choices about where and who they live with, and also with the minutia within how to live their everyday lives for example, how they wish to be supported in personal care. They also seek to promote competence by developing individual skills to enable social integration. Allied with

this is enhancing respect afforded to individuals as fully participating citizens, by maintaining positive reputations, and finally ensuring community participation and personhood (Forest and Pearpoint 1991). This is achieved through supporting an individual's natural relationships with friends, family and circles of support, to fully embrace activities within their local communities. The aim is to increase a person's individual social network, ensuring that not everyone in it are paid workers, or involved in learning disability service provision, or campuses (Brown and Smith 2001; Todd and Gilbert 2005).

There is an ethical point to consider here, and that is why is there a need to develop these special ways of supporting people with learning disabilities? There is possibly a danger that in ensuring egalitarian principles of rights, choice, control, social acceptance and inclusion, a dependent view is produced. This reinforces the view that people with learning disabilities are different, because they need specialist assistance and support from others.

Using this analogy people with learning disabilities are deemed to lack the ability to function as an independent person. This requires a need for specialist assistance, and is the result of an aetiological cause, namely their learning disability (Honderich 1995). This reinforces an individual's dependency on others, and as a consequence a view that personhood is not accorded.

A CONSIDERATION OF WHY PERSONHOOD IS PRECLUDED

In seeking to define personhood it may be far easier to describe non-personhood. These definitions will depend on the cultural norms and expectations in which they are situated and also the environment to which they relate. An example of this can be seen in Native American culture (Neihardt 1988). When Black Elk

describes the battle of the Little Bighorn he describes the soldiers as “Wasichu”. This is a non-descript term which literally translates as “taking the fat”, used in this context to describe people who were coming to “rub out” the Lakota nation, destroy its culture, and rob them of their right to hunt the “four legs” (Bison). After the battle he describes how young boys and women stripped the soldiers, and mutilated their bodies. He also describes how wounded soldiers were scalped alive, and hacked to death, often by young braves. Such apparently inhumane treatment appears unacceptable to those outside of this culture, but there are many analogies with such treatment in Western Society. Particularly, in relation to the treatment of those viewed as different. This was illustrated when the University of Yale conducted its well-known prisoner experiment (Haney, Banks et al. 1973). The students playing the parts of guards inflicted pain, punishment and individual humiliation on the student prisoners. The treatment inflicted was so extreme that the experiment had to be stopped after two weeks, because some of the prisoners were developing mental health conditions.

The writings of the survivors of the Nazi Holocaust in the Second World War further illustrated how it is possible to treat people in the most terrible ways imaginable, if they are not designated as persons (Vania Waxman 2006). Nazi propaganda defined Jews, homosexuals, the disabled, and political prisoners as non-Aryan, and inferior to the German race. Prisoners were selected on arrival and the women, children, old and disabled, went immediately to the gas chambers. The others were to become slave labourers. All the selections were made by doctors. Prisoners were shaved, stripped, deloused and tattooed as part of the de-individualising process (Levi 1998). In the camps the individual ceased to exist,

guards treated prisoners as sub human “Häftlinge”. This gave them permission to abuse individuals in the most unjust ways. There is a commonality amongst the survivors not to become a “Muselman”. This describes the non- human, the individual so brutalised and tormented by the experience that he loses the will to live. He takes neither nourishment or care about his own dignity, a non- person who work and labour in silence, devoid of the divine spark, the will to live,(Frankl 2004). Bettelheim makes an interesting analogy to “Muselman” when describing Thus Höss commander of Auschwitz:

“ he divested himself so entirely of self respect, self love, feeling and personality, that for all practical purposes he was a machine functioning only as his superiors flicked buttons of command ”.

Remnants of Auschwitz: The Witness and the Archive, Pg 57 (Heller-Roazen 2002).

Many of the survivors speak of their will to survive and bear witness to the atrocities. In order to do this the individual had to preserve a degree of dignity and self- respect. One of the key factors affecting survival was to look on this terrible situation as a provisional existence. The individual ceases to live for the future and lives for the day, but he still has hope, and has in his mind thoughts and values. This process of making and remaking ourselves is a particular component of what it is to be a person. There is no utopia without a tension between a denunciation of the present that becomes so intolerable, and an annunciation of a future yet to be lived experienced and created (Freire 2004).

The use of these individual narratives can often uncover the most descriptive accounts of individual and mass behaviour in the most extreme of circumstances (Bettelheim 1943). Frequently these illustrate a resignation to torture, brutality, and loss of self respect. As a result there develops a feeling of utter indifference amongst the brutalised. It is at this moment that the repressed become emancipated since nothing else matters. They are now free from fear and although not actually happy with their circumstances, are accepting of their lot within themselves, individually and collectively, (Freire 1993).

People with learning disabilities have provided a number of narrative accounts relating to their treatment in institutions, and by those who are employed to support them. One of the frequent conflicts appears to relate to the lack of personal agency on the part of the person to function in an autonomous way. This results directly from agencies seeking to control, confine, organise and structure individualised agency within the confines of a highly bureaucratic organisation (Graham 2009). Tom's story highlights this with a particular emphasis on individual lack of agency. This arose as a direct result of services in his area instigating service eligibility criteria in order to access certain services. It also illustrates an increasing awareness by people with learning disabilities that they can advocate for themselves as described in the following extract:

Tom states: "I had been in cherry orchard for twenty seven years. I thought well, I can't stand it anymore, I have had enough.(laughs) I'd had enough after 27years".

Oral History, Learning Disability and Pedagogies of Self. (Graham 2009), pg 86

There is an episteme here with regard to the treatment of people with learning disabilities by professionals with a particular emphasis on the prescribing of psychoactive drugs, and their treatment in institutionalised settings. Here the emphasis is on serving many quickly and in the cheapest way, for example in many nursing homes and hospitals there is insufficient time given to feeding people who are frail or need help with feeding (Wolfensberger 1984). Also in hospital settings many people with learning disabilities have received less than adequate care, reinforcing a need for professionals to adopt an attitude that recognises the need for compassion and humanity (MENCAP 2007). It also requires empathising with the person's current individual experience and adopting the principles of justice, citizenship, and social and moral equality. There also needs to be a recognition that everyone is equally important, and should be treated in an equitable manner. Of particular importance is a recognition that the professional may have expertise in understanding specialist treatment or care required, but the individual is an expert in themselves, and how they wish to live their life (Fulton 2014). This is a view shared by many self-advocates, families of people with learning disability, and person centred planners (O'Brien and O'Brien 2002; The Foundation for People with Learning Disabilities 2002).

THE MEDICAL MODEL AND THE PROFESSIONALS CLINICAL GAZE

One of the main positions adopted in the field of learning disabilities is the medical model, but it equally applies to people with mental and physical disabilities (Barton 2001; Barnes 2007). This theory applies scientific rationality to the study of people with disabilities and illness, and classifies, depersonalises and presents the individual, not in terms of positive attributes but in terms of impairments (Hayes and

Hannold 2007). This in turn supports a medical model of health where people are viewed with a “professional gaze” (Laing 1968; Foucault 2007), and not in terms of whom they are, and what capacities they have within themselves to develop and grow as a person. They are viewed in terms of an interesting case, to be professionally studied, classified and hopefully successfully treated (Oliver 1990). Using this approach a person with a mental illness such as schizophrenia would be viewed by a professional as a clinical case to be studied and treated, not as a person, a fellow human being. Allied with this approach is the segregation of people who are different from what society views as “normal”. To protect society from their deviant influences, and also to protect the vulnerable person from harm, they are segregated away from society in institutions or therapeutic communities. Here it is hoped they can be treated and a few rehabilitated and returned back to society. Often the truth is that people treated in this manner never return to society, or the original communities where they lived and grew up. Social networks and connections are lost, and they become institutionalised and stigmatised (Goffman 1961; Foucault 2007).

The original paradigm that supports such treatment is that disabilities are viewed as the individual’s problem. A person with impairment is viewed as the result of a personal tragedy, since it is their body that has a loss or restriction with regard to function. Typically the language used to describe people with disabilities concentrates on negative aspects, for example loss of functional ability, or a restriction of ability. Indeed the World Health Organisation definition of impairments emphasises these points (World Health Organisation 2001):

Impairments: are problems in body function or structure as a significant deviation or loss.

Body functions: are the physiological functions of body systems including psychological functions.

Body structures: are anatomical parts of the body such as organs, limbs or their components.

(World Health Organisation 2001), *International Classification of Functioning, Disability and Health (ICF)*.,Pg 12

The classification defines learning disability within a global category of intellectual functions:

B117 Intellectual functions.

General mental functions, required to understand and constructively integrate the various mental functions, including all cognitive functions and their development over the life span.

Inclusions: functions of intellectual growth, intellectual retardation, mental retardation and dementia.

International Classification of Functioning, Disability and Health (ICF).

(World Health Organisation 2001), pg92.

The World Health Organisation also now recognises personal and environmental factors as contributory in their classification, on the pretext that they

are not part of the individual's health state or health condition. There is recognition that they will have an impact on any individual interventions for treatment and support. This includes factors such as lifestyle, gender, ethnicity, personal experience, and individual characteristics.

The overall aim of the classification is to enable a person with a disability to be accurately classified wherever they may live in the world. Some authors view this as a great step forward as the classification introduces a new approach which conceptualises disability in terms of underlying health issues and conditions. It also provides a taxonomy in which standardised numeric codes were developed, enabling greater clarity for clinical and administrative purposes (Simeonsson, Leonard et al. 2003).

Using this approach the person is viewed as a passive recipient of expert professional intervention. There is another viewpoint also to consider perhaps rather extreme but rather than the professional being viewed as the saviour of the individual, they become instead viewed as objects of oppression (Millett 1993). By classifying, studying, assessing, looking at impairments and ways to treat them, the individual is not freed by professional gaze but becomes imprisoned by it. Indeed it has been suggested that the establishment of discursive formations, the way words and concepts are organised stratigraphically throughout history has greatly influenced how society views individuals who are different from society's view of "normal" (Foucault 2007). Through the use of power those who are "deviant" and do not fit society's views are excluded, stigmatised, socially isolated and controlled. Through oppressive techniques they are quashed, reducing individuals to compliant docility (Baggini and Fosl 2003). There is also a view that people with impairments

are defined within such a Foucaultian model, since it suits the requirements of the socio/economic and political regime at that time. The way the United Kingdom's government administer Disability Living Allowance (DLA), is an example of this approach as is the World Health Organisation's taxonomic classification of disability. Both these policies reinforce the production of an impaired individual. In order to receive DLA the individual has to complete a questionnaire. This requires the disclosure of a great deal of intimate information, mostly based on impairments and what the person is unable to do. This reinforces in the individual the view that they have an impaired body. It also reinforces society's view of impaired bodies by setting them within a "scientific" classification. This moves the individual's impairment into a classification maintained by professional knowledge and technology. The power and control over their life shifts from the impaired individual, to the professional. By qualifying for DLA the individual is accepting, and reinforcing the political view that they are "unproductive" members of society (Tremain 2001) .

This is particularly relevant to the abuse suffered by people with learning disabilities in the recent Winterbourne view investigation (Department of Health 2012). Individuals were placed in a private treatment facility, in some cases many miles away from their home, family and friends. Whilst there many were subjected to physical restraint by staff, over 500 cases were reported in a 15 month period. Agencies responsible for placements failed to respond to concerns, for example numerous visits to local hospital Accident and Emergency departments by the same individuals, frequent attendance at Winterbourne view by the local police, and safeguarding alerts that were not acted upon by the Local Authority. There was poor staff training, lack of leadership and management, and what has been described as

a punitive, closed culture. Here visitors and relatives were actively prevented from seeing the top floor wards, and individual bedrooms (Department of Health 2012). Thankfully, an enquiry resulted in closure, police arrests and a number of prosecutions of staff members. There were also a number of recommendations, which are described in detail in the policy section of this thesis. However, one of the key actions was to implement key principles of care, which put the person and their family at the centre of all services and support. It was suggested that services must be person centred, and individualised. The person must be treated as a whole person, not an interesting case to be studied, and treated. The person should be supported to remain at home within their local community, not sent miles away and segregated away from society. Finally if the person needs additional support it should be available locally, and where this is not possible innovative solutions should be jointly commissioned by agencies (Department of Health 2012) .

These actions should reinforce the positions proposed in this thesis that people with learning disabilities should be viewed as people first, with the same civil and moral rights as anyone else in society. It can be seen that problems arise in “closed cultures” when individuals are medicalised, viewed as problems, not positively regarded as individuals, and treated in ways which seek to control, confine and force conformity to an anti- social situation (Department of Health 2007). Individualised care and in particular person centred care, and planning are viewed as a first step towards a transformation of treatment services for people with learning disabilities.

It should also be appreciated that the manner in which disability is viewed and classified has changed considerably in the last decade. This has resulted largely as a result of individuals with disabilities advocating strongly for a social model of disability to be recognised by society, and its political and legal institutions, including the medical professions (Shakespeare 2008). Disability is described as a social problem because disabled individuals are prevented from accessing services and facilities. This is not based on an impairment paradigm, but rather a systematic failure to ensure people with disabilities are fairly provided with the means to access mainstream provision. It views disability as a form of social disadvantage, not the result of a personal attribute, or individual characteristics. This approach has been criticised as unduly Marxist, in that once the social dimensions of disability have been resolved no serious impairments will remain. Thus, it fails to recognise a variety of physical and mental conditions that will remain with the individual throughout their life. Although some symptoms can be alleviated through successful medical intervention and treatment (Harris 2009).

It could be argued that the “Government of disability”, how it is described, classified and administered within a socio/political framework is a result of many interrelated factors. These include the political party in power at the time and its policies and legislation related to disability, the socio economic climate, the affected individuals and their own response to their condition, and medical and theoretical responses to disability. A new way of conceptualising disability has been proposed between the two extremes of the social versus medical model debate. This involves the use of ethical, political and philosophical enquiry emphasising that these disciplines whilst lacking scientific empiricism, add to any debate on disability

because of the theoretical scrutiny typical of these disciplines. This approach utilises an example of the social construction of some impairments, illustrating how they may be defined as disability in some social situations, but talents in other settings. For example the hypotonic muscle tone seen in some people with Down Syndrome can enable individuals to excel in music and movement due to increased muscle and joint flexibility (Louhiala 2009).

The key appears to be focusing attention on the individual, and how their condition affects them individually and collectively. Rather than oppressively seeking to define, classify and technically administer their condition or impairment. By working collaboratively together within the framework of individualised care and support, positive spontaneous solutions can be found. This results in the promotion of individual choice, control and freedom to live the life they would like, within their local communities (Finkelstein 1981).

THE THEORETICAL FOUNDATIONS OF HUMAN THOUGHT AND BEHAVIOUR

Philosophers have considered the question of what it means to be human for centuries. It is an intellectual activity requiring a high degree of generalisation, and a reliance on reasoning. It is concerned with “thought about thought” as opposed to first order thinking about particular subjects, or what is observed as in science and history (Bullock and Trombley 2000). It is very closely linked with theoretical ideas concerned with ethics, morals and what it means to be human. There are thought to be certain values which are central to functioning as a human. These values lead to

rights which are grounded in the virtue of being a human being. One of these is human dignity, and the core concept to this is that human beings have a capacity to reflect on, to choose, and pursue what they consider a good life, (Tasioulas 2002). There are many correlations with this and Cartesian phenomenology, “Cogito ergo sum” I think therefore I exist, (Smith 1998). It has also led others to consider an essentially metaphysical question regarding the nature of human thought (Badiou 2008). So part of being human and therefore a person involves an ability to reflect, to be moral, to love, dream, aspire and to be rational, conceive and understand the world. There is also the ability to be aware of him/herself as a separate entity, to remember the past, to look forward to the future and use his or her imagination in ways that go beyond basic urges, and behavioural responses to stimuli (Overskeid 2007). Some argue that these are not traits confined just to humans (Fernandez-Arnesto 2004). Others consider these a dichotomy for man. They are seen as a burden, a curse, because of his self awareness he constantly questions his existence, his life, and ultimately his own death (Fromm 2008).

Fortunately such a pessimistic view is not shared by everyone. Hume’s treatise of the human mind developed a halfway house, viewing human thought as distinct psychological processes which went beyond cause and effect, and the measurable and observable (Hume 1993). The interdependent relationship between two variables is not necessarily scientifically measurable or defined in a relationship. The uncertainty about the nature of human knowledge is part and parcel of being human. Hume thought knowledge should never be taken for granted, and scientific reasoning should not preclude an element of doubt (Deleuze 1991). Deleuze sees no human right as an inherent right of man. Rather he sees terrible situations arising

in life and views such acts as matters for the courts or as he terms it “jurisprudence” (Deleuze 2004). This is in direct contrast to the approach taken in the field of learning disability services where there has been significant change in Government policy to reflect human rights issues, (Dearden-Philips and Fountain 2005). These are discussed in greater detail in part 3 of this chapter.

An alternative viewpoint comes from Aristotle’s concept of hylomorphism (Christofidou 2009). The proposition is that every living thing is a combination of matter (hyle), and form (morphe). Also that every living thing has a psyche, but psyche used in this context by Aristotle has no relation at all to the psyche or soul described in Descartes’ dualism. It is used in this context to mean the principle for life. However, Aristotle deserves a mention in seeking to ascribe personhood and human thought because he described the idea of practical reasoning. This can be described as reasoning out the good. These ideas later resulted in debates about what makes a good life, and the qualities a person should have, and have produced ethical enquiry and debate (Kenny 2002). It also includes the concept of academic Eudaimonia. This is ascribed by Aristotle as being the most divine part of being a human, and is the activity of theoretical contemplation. It also involves contemplation on the full range of human life and actions, and involves moral virtue and practical wisdom. It perhaps gives an insight into human nature and personhood. It involves perception, reason, emotion, and ultimately action and interaction. These are produced as a result of transcendental thought. This occurs within a being whose thought processes have gone beyond simple cause, and effect, or flight and fright responses to the external world (Oksenberg Rorty 1980).

There needs to be recognition that human behaviour and personhood are linked with social behaviour, since human beings are inherently social beings. This view has resulted in the development of the school of symbolic interaction (Blumer 1969; Burns 1992). In this model man is part of a social world and interacts with his environment, including objects and people. Human behaviour is shaped and influenced by the nature of this interaction. It is not just a response to stimuli in an unconscious manner, but meaning is developed in the interactions. As a result, the individual or group, consciously interpret the meaning of interaction, and deal with it in a certain way. Goffman described this in some detail when he developed his dramaturgical theories. A person is like an actor on a stage presenting different actions depending on the script being played, for example when visiting a person with a learning disability for a consultation there is an expectation that professionals take the role of an authoritative medical professional. The person and their family is expected to receive advice and carry out any actions advised. If the roles were reversed utter confusion would result (Goffman 1990). Unfortunately, people with learning disabilities are often precluded from this approach since they are often defined often in terms of lacking intellectual ability, or the inability to develop informed consent, or practical reasoning (Department of Health 2005; Department of Health 2007). Often they are thought not to have opinions or ideas of their own. They will have spent most of their lives being told what to do, and how to behave by others. With little recognition or consideration that, they may have latent abilities and talents, that have not yet been discovered. The reality is that often people with learning disabilities not only can assume roles, but also provide new insights by speaking from personal experience. However, the key is to enable individuals to be

fully prepared to take on these roles by learning new skills and having effective support available (Whittaker 1994).

Mead (Nye 1977) interpreted Goffman's approach to suggest that people are continually reflecting on themselves and how they are viewed by others. The interaction of the self concept (I) and the perceived view of other (Me) are central to Mead's approach (Blumer 1966). We internalise how we think others view us and present a Me directly as a result of socially interacting with others. So it follows that for a person to be integrated into a community, and fully accepted as a person he or she has to interact with it, and the people who are part of it. Mead also conceptualised the notion of relexiveness. This involves the individual turning back what is experienced to within themselves. He viewed this as an important part of experiencing social situations. The individual adjusts how they appear to others as a result of this internalised process. There is a connection with Sartrean existentialism in this discourse particularly the self reflection, and the individual choosing to appear in a certain manner, depending on their own position in the "world", and the social interaction taking place. Blumer (1980) proposed that human action was not caused by a release of an inbuilt unconscious way of behaving or tendency, but was the result of an action by the actor (or individual) reacting to another actor in a situation. There are analogies with Goffman's theories, and implications for people with learning disabilities, particularly those who have limited experience of social interaction.

By coaching, role play and direct observation of others and developing working alliances, people with learning disabilities can quickly learn by example to assume valid social roles (Brechin and Swain 1989). However, in order to achieve a

valued social role there has to be an acceptance of the person with learning disabilities. This has proved to be particularly challenging particularly within the context of recent social policy aimed at social inclusion. A Swedish study examining adolescents attitudes towards the community acceptance of people with learning disabilities supported this assertion. The findings indicated that people with learning disability still faced considerable discrimination. Individuals were accepted if they had a mild learning disability, but only in leisure situations where they were perceived as causing less damage or disruption. People with learning disabilities were still being viewed as “other” in de-valued, stigmatised roles in spite of considerable legislative attempts to ensure their social inclusion. A resolution to this difficulty appeared to be educating adolescents at an early stage to accept individuals as people first , and valued members of society (Hastings, Sjoström et al. 2001).

I favour an approach built on the concept that a person has a first person perspective, and a human person is a human organism capable of thinking in this manner (Rudder Baker 2005). In other words it is the ability to think of one’s self from within. This sets human persons apart from other species because they have an ability to perceive themselves in a sub-conscious way, a transcendental field of thought born from within. This may be viewed by some as purely a philosophical argument. However, philosophical thought is composed of a process of active reasoning and generating new epistemological theories. There has been a call for this way of thinking to be applied in the field of learning disability research (Ball 1994; Allan 2011).

There has been a renewed interest for researchers to employ “thinking otherwise”, as a way of proposing new theories in the field of learning disability (Ball 1994). This is supported by (Allan 2011), who introduces philosophers of difference into her research. She specifically cites the French philosophers Deleuze, Guattari, Derrida and Foucault as examples of this category, since they have all worked on enabling minority groups to receive greater recognition within society based on their work, which is essentially political in nature (Deleuze 2004; Glendinning and Eaglestone 2008). She views this research a “philosophy of affirmation” which is described as a belief of the future, in the future. It provides a creative optimism since it provokes existing institutional structures, power and control by challenging the status quo. Often with new and imaginative concepts which break down existing barriers, enabling valuing diversity in all its forms (Kaufman and Heller 1998). By utilising such philosophical theories a new way of conceptualising learning disability can be achieved. This enables individuals to think differently, and provides new orientation and direction, aiding practice within learning disability research. This has many similarities with my own research approach.

As an individual involved in person centred planning, I view the person as an individual in their own right. This implies that there is something about being human that is special, and something about the particular person we have chosen to support that draws us to him or her. Person centred planner’s talk of qualities and gifts (Falvey, Forest et al. 2003). These are not esoteric terms, they describe something about being a person, a human that is special, particular and difficult to define (Mount 2002). It also means the falsification and rejection of approaches that are behaviouralist, psychoanalytical, and professionally/medically dominated.

The belief system underlying the entire person centred planning tools, is that all human beings are more alike than different. They share common basic needs, there is no them and us, just we (Falvey, Forest et al. 2003).

PROFESSIONAL DISCOURSES RELATED TO PERSONHOOD

Historically the dominant professional discourse in learning disabilities has been that which relates to the medical model described in the previous section of this thesis. This model has been viewed by some as maintaining the privileged role of professional domination over people with learning disabilities, their families and carers. The reality for many people with learning disabilities is that although Government policy and professional practice has supported the view of building professional partnerships based on civil and moral equity, choice, inclusion, ethical treatment and shared decision making, there remains inequality(Nunkoosing 2000).

Race (1999) further suggests that that these new initiatives have been severely underfinanced, and there is still an overemphasis of the medical model in both academia and professional training. This was discovered following a review of learning disabilities in health and social work training programmes. He suggests an approach is needed that changes “hearts and minds”. What has developed as a result appears to be a professional paradox. Professionals and services now find themselves in conflict with the new orthodoxy of service provision and the historically dominant professional ideology. This shift is founded partly upon the social model of disability, and an increased emphasis on promoting professional partnerships with service users giving the individual increased autonomy, choice and control.

Daley(2002) describes this paradox in her study of professionals working in learning disability services in Scotland. She found that newly qualified staff fully

supported the new integration role. In opposition she found those professionals often qualified for many years (and described as Dinosaurs by one respondent), who adopted a paternalistic controlling attitude. Clearly these tensions and conflicts could affect the people with learning disabilities both groups seek to support. The suggested solution to this problem was creating a shared ideology whilst acknowledging professional differences, but requiring a consistent, value based approach. This is a view supported by many learning disability policies and professional practice guides and has resulted in a number of innovative solutions to training professional teams. The development of specific occupational standards which informed a multi-professional learning disability team outlined by Jowett and Wellens(2000) is an example. Generic skills based competencies were developed for the team including overarching values founded on the principles of social role valorisation, social integration, increased choice and control for service users. It is suggested that this will improve professional practice and service delivery by offering a more focussed professional intervention. Also it will improve the user experience by ensuring the right person visits, at the right time, giving the support required.

There also appears to be a developing debate about the definition of professionals working in learning disability services. The term usually refers to an individual who has completed formal training in a professional discipline for example, social work ,nursing, psychiatry or psychology. Increasingly people with learning disabilities are supported by care staff and key workers, and many of these have had formal training and therefore should be included (Gillman, Swain et al. 1997).

Although I have described other medical professions throughout the preceding sections of this thesis I intend to illustrate discourses relevant to learning

disability nursing, since this is my current profession. It is important to recognise that in recent years this profession has undergone many changes, not least of all in the manner that nurses are educated and trained.

Learning disability nursing as a profession has tended to be based on a medical model of education and professional practice. The terminology used to define the people supported tends not to define the characteristics of the person, but rather offers a global, generalised picture of an individual with impairments in need of expert help (Speraw 2009). People are also defined in depersonalising terms for example patients, clients and often nurses and learning disability professionals describe people as “my patients”, and “my clients” as if there is ownership of the individual. When professionals focus on impairments and disease processes alone they lose sight of the individual and fail to recognise the person’s needs for compassion and empathy. If one views professionals as agents of oppression in that they exert control over those they treat, medicalise the person into a condition, use professional terminology that seeks to de-individualise and confuse for example, intervention, and assessment (French 1996; Davies 1998) personhood can easily be lost and with it feelings of self worth, the individual becomes a “Musselman”. This definition refers to the non-person, not a later negative description of a Muslim (Niewyk and Nicosia 2000). It can be seen that in order to change these views it is essential to have close contact with people with learning disabilities, their carers, and families, and build working partnerships.

One of the key issues in encouraging people to live their life as they wish is by providing professional help when asked, or when the safety of the person is put at

risk, or they could harm themselves or others. Self- determination and empowerment are important for everyone, not just people with learning disabilities. However, in order to be empowered people need to recognise and understand their powerlessness, feel strongly enough about their situation to want to change it, and feel capable of changing the situation by having effective information and support (Naidoo and Wills 2000). This support can be at the individual level, for example in the form of self- help skills, or at a community level through local government policy initiatives, and direct action groups. Some authors view self- determination as important not just for individuals, but for groups and communities (Tones and Tilford 1994). If self- determination and empowerment is defined as the growth of an individual's ability to direct their own actions and influence their environment, then it can be seen that there are very strong links with the aims of person centred planning and promoting personhood (Henderson and Pochin 2001). It can also be used as a way of encouraging self- advocacy through promoting individual expression of choices and aspirations (Smith 2006; Smyth and Bell 2006).

Many involved in the disability rights movement view self- determination at two levels. One is associated with policy and welfare consumerism, for example Valuing People Now (Davis 1996). The other is concerned with individuals who use disability services demanding a voice in shaping services, representing an expression of individualism but collectively (Finkelstein and Stuart 1996), and also calling for a change in the political interpretation, and provision of disability services (Orem 2001; Tregaskis 2002; Goodley 2005). Recent moves towards a more social model of disability and health provision have resulted in major changes in Government policy which promote choice, rights, and social inclusion for people with

learning disabilities (Department of Health 2001). The white paper Valuing People Now promotes personalisation of services with individuals taking control of their own budgets, instead of professional gatekeepers being in control (Department of Health 2009).

The changing role of learning disability nursing supports the view of personhood, by actively encouraging social integration. Through supporting and enabling individuals to use mainstream services, and to support individuals and carers as close to their homes and communities as possible (Department of Health 2007). Changes to learning disability training have also ensured that personhood, autonomy and rights are key parts of the national knowledge sets, (Skills For Care 2009). Many services now employ people with learning disabilities as trainers, keynote presenters, and active participatory researchers (Millard 2009). However, research activity in the health service still tends to be dominated by medical, empiricist approaches, with an emphasis on clinical trials. This approach needs to be challenged by developing qualitative research approaches which encourages active and non tokenistic participation by people with learning disabilities, for example those based on action research, and visual ethnography (Pink 2005).

There still remain a few challenges, there is a need to stop the screening of people out of services on the basis of intelligence quotient alone (Whitaker 2008). If someone has a disability there should be acceptance that when they or their carers approach services they are in need of some service provision. A great deal of time and money is wasted on gathering professional assessments that prevent individuals accessing services so they are passed onto another service. This is not only

frustrating for the individual, but can be very damaging to their own view of themselves as a person.

Indeed the question of I.Q. testing remains an active debate. Some suggest that it is arbitrary and unhelpful since the test can be influenced by individual mood, motivation and degree of literacy. Also the test itself is largely framed within Western cultural requirements, clearly disadvantaging those from other ethnic backgrounds. Supporters of testing suggest that by identifying people with low I.Q. early on, the appropriate help and support can be provided quickly. This approach has for example, assisted in establishing a connection between young people with low I.Q. and later offending behaviour (O'Brien 2001). Valuing People (Department of Health 2001), recommended that I.Q. alone should not be used as a method of identifying individual service eligibility. Perhaps the solution is to use I.Q. testing as one method of the multi-professional assessment process. This would include taking into consideration the views of the individual, and where appropriate those of family, carers, and other professionals. A holistic picture of the individuals needs can then be developed, and the assistance that should be provided (Reiff, Gerber et al. 1993).

There is also still an emphasis on safeguarding people with learning disabilities. This further reinforces the individuals and societies views that people with learning disabilities are not really persons, but have a childlike status which results in them needing state protection (Department of Health 2007). However, I also accept that there are occasions when people genuinely lack the capacity to make informed decisions, and need assistance to keep them from harm or exploitation (Department of Health 2005). The changes to the Mental Capacity Act (2005) ensure that it is accepted that every adult has capacity, and the responsibility

rests with professionals to prove individually why this is not the case. This greatly reinforces the concept of personhood, in that all adults are afforded the same rights.

On a personal level I now fully embrace the view that there are alternative ways of supporting my professional practice, and this includes an active appreciation of postmodernist critiques related to health, disability, and personhood. I also feel that person-centred planning can encompass all of these, but importantly it should also give people the chance to make their hopes and dreams a reality, and get the life they really want. The challenge is to ensure that society and specifically the communities in which people live, fully accord personhood to people who are “differently abled”. This is achieved by an acceptance that they have a moral and civil responsibility to do so.

There also needs to be recognition within professional groups and services that people must be treated as people first, and that individuals are part of humanity and have a right to be treated justly and with equity. People exhibiting behaviour that challenges others often do so with very good reason. These should be investigated within the environments and contexts in which they occur before individuals are medicalised, segregated and depersonalised (The Foundation for People with Learning Disabilities 2005; Department of Health 2009).

It is very easy to use deficit dependant models to exclude individuals from being a fully functioning person because they lack cognitive abilities. The challenge is to accept people as people, human persons with their own life experiences and gifts, and ensure they are fully included as active participants in society.

SECTION 3

PERSON CENTRED PLANNING

INTRODUCTION

Person centred planning is a method of life planning that evolved in America and Canada in the 1970s and 1980s. It arose due to a group of like-minded individuals meeting and agreeing that the current methods used in supporting people with learning disabilities were far from inclusive, and promoted a system driven medical model of service provision (O'Brien and O'Brien 2002). As a result a number of different techniques (often termed tools) developed, but at their centre was a core belief that there must be increased personalisation of services. This promotes individual choice and control over the way the individual lives, and the way in which they are supported by the people they have chosen to support them.

This is achieved only by carefully listening to the individual and their personal interests, dreams, wishes and desires. It challenges individuals and services to value each person as unique, recognise untapped potential within the person, and consider a variety of possibilities. Often this involves thinking creatively with a positive outlook un-constrained by labels, service requirements or resource deficiencies. In this way it builds on the principles of normalisation and social role valorisation (Brown and Smith 2001; Race 2003).

There are a number of ways in which this is achieved. Firstly it promotes person centredness and personalisation. This involves carefully listening to the individual's voice, and acting on their aspirations and wishes. Secondly, it utilises the individual's family, and wider social network to assist in engaging with the community at large. This promotes social inclusion, and also prevents an over reliance on

specialist learning disability services. Finally, it supports the concept of social capital where the emphasis is on promoting social inclusion, support networks within local communities, and reciprocity in relationships with all community members. In order to achieve these aims there needs to be a radical change in the way life planning takes place (Bates and Davis 2004; Mansell and Beadle- Brown 2004).

Person centred plans are one of the ways in which life planning can take place. There has always existed in learning disability services a number of care and life planning methods, variously described as individual service plans, individual programme plans or care plans, but the degree to which they have been person centred has been questioned (Dowling, Manthorpe et al. 2007). At best valiant attempts were made to produce a picture of the person and their individual needs, within the confines of service pressures and administrative requirements. At worst they appear to represent a paper exercise, designed to fulfil local and national service requirements and audits. The introduction of Valuing People, and Valuing People Now (Department of Health 2001; Department of Health 2007) and the resulting focus on self directed support and citizenship models of service provision and design, has seen the arrival of individual service designs, person centred support plans, person centred care plans, and educational reviews. All of these share a number of characteristics, and are regarded as appropriate ways of planning with people with learning disabilities (Sanderson 2000; Holburn and Vietze 2002).

Firstly, the individual is the focus of the plan, planning takes place in order to meet their needs. Secondly, families ,carers, and friends are included as an integral part of the process. Thirdly, planning reflects what is important to the individual now and in the future, and includes how they are going to be supported. Fourthly, the

plan assists the individual in joining their local community, and encourages their communities to become involved in supporting the person. Finally, the plan is developmental, it is regularly revisited, reviewed and amended when individual circumstances change, and a plan of action is provided with timescales (Department of Health 2010). This is in contrast with organisationally driven paternalistic planning which has often been incorrectly described as person centred (O'Brien and O'Brien 2002). In Control the organisation established to enable increased personalisation, produced some guidelines on what constituted a person centred care plan (Sanderson and Tyson 2014). It included the following:

- What is important to you?
- What do you want to change?
- How will you be supported to make change happen?
- How will you spend your money?
- How will your support be organised and managed?
- How will you stay in control of your life?
- What are you going to do to make this plan happen?

Making your support plan: an easy read booklet (Sanderson and Tyson 2014) pg 3.

AN ALTERNATIVE APPROACH TO LIFE PLANNING

Mount (2000) defines a system centred model as focusing on labels, emphasising deficits and needs, investing in standardised professional assessments and testing of individuals, generating written reports and professional judgements,

and decision- making. Individuals are viewed in the context of how they can fit into current specialised service systems, and people are socially segregated by emphasising their differences.

Figure 1. An Illustration of Personal versus Organisational Needs.

Personal needs Organisation needs

<ul style="list-style-type: none">• To be seen as a person. with needs and aspirations.• To be listened to and made to feel special.• To have people around me who are interested in me.• To have a future life goal.• To be connected with my community.• To have a life plan.	<ul style="list-style-type: none">• Effective utilisation of resources.• Implement economically efficient changes.• Implement a systems culture within a legal framework.• Ensure all risks are assessed.• Implement effective recording and data capture.
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Adapted from *Person-Centered Planning: Finding Direction for Change Using Personal Futures Planning*, (Mount 2000), pg 12.

The principles described in the personal needs section of Figure 1, are utilised in the P.A.T.H (Planning Alternative Tomorrows with Hope),(Pearpoint, O'Brien et al. 2001) and build on the characteristics required for a person centred approach. This is one of a number of different methods/tools employed to develop a person centred plan. Only those which have been utilised to support Keith will be discussed in detail in this thesis, since there are many different models or tools. It is important to recognise that the method chosen must be relevant for supporting the focussed person. The individual must be able to understand the methodology, and participate

as fully as possible in developing the plan. Different methods can also be adapted to suit individual needs rather than applying a rigid format .The key is to fit the plan to the person not the other way around (Sanderson 2000). Keith's P.A.T.H and other graphic representations of his plan illustrate this (these can be viewed in **Appendix 5**). They contain mainly words and few graphics, because Keith can read, and didn't feel he wanted many pictures. He felt they were "childish", and demeaning. Although graphic representation is a key requirement of many person centred planning methods (Pearpoint 2002; Jupp 2003; O'Brien and Pearpoint 2004) .

P.A.T.H contains an additional three key essential elements (Pearpoint, O'Brien et al. 2001). The first is facilitation by a team. By working as a team collaboration and co-operation takes place. All the team members strive to work together for the benefit of the individual they are planning with. The second phase of the process is that of graphic facilitation. By representing the individual's hopes, dreams, and aspirations graphically, without the major use of words, all the team members work together in an imaginative, creative and new way of planning. Not only does the individual get the message that they are important, but that the process is fun, and the team members have a pleasurable experience.

The last phase is team empowerment. All the power and control rests with the team and the individual .They decide together what is important and what they will do next, who they will engage with, and what the most important things are for the person. Keith's P.A.T.H can be found in the appendices (O'Brien and Pearpoint 2004).An important part of P.A.T.H is the North Star. This encapsulates the person's dreams; it is an expression of the person's identity and is often graphically represented. The dream helps the person and the group find the way through a complexity of information. Pearpoint (2001) describes it as akin to finding a route

through an unknown forest. It often encompasses ideas and values, and enables the group and the person to focus their activities to try and achieve that goal, or at least go some of the way along the trail.

It is important to recognise that some of the dreams may appear unrealistic but it is important not to dismiss them. The idea of the North Star arises from Native American spirituality and culture. Dream catchers are important within some Native American cultures, and represent a vision or a point to head towards.

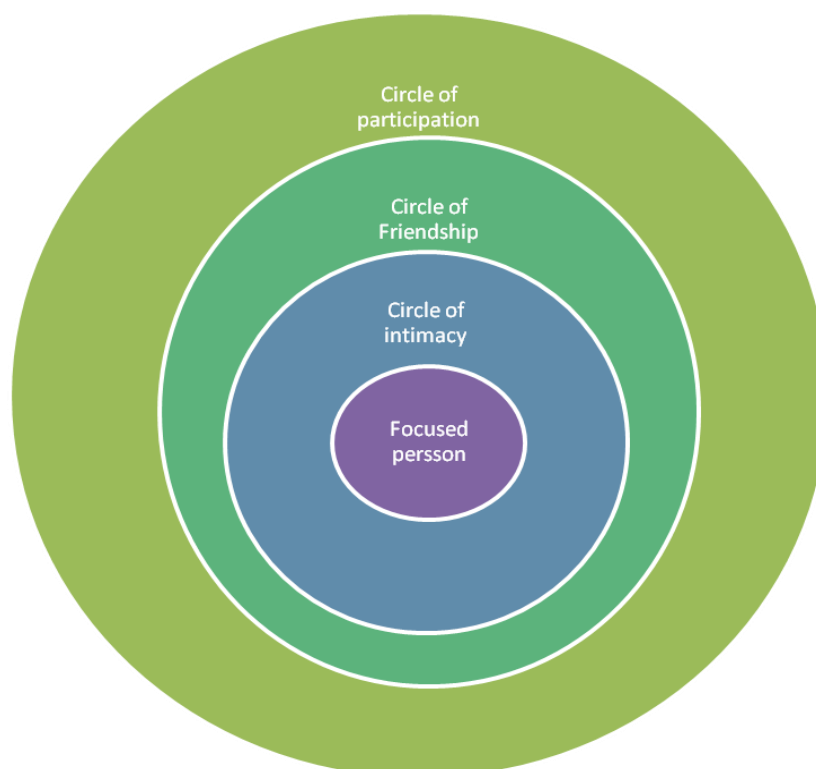
“A vision without a task is a dream. A dream without a vision is drudgery. But a vision with a task can change the world.”

Black Elk cited in *P.A.T.H: A Workbook for Planning Positive Futures* (Pearpoint, O'Brien et al. 2001) , pg 20.

Keith's person centred plan also contains a relationship map that shows who is important to him. This is often described as a doughnut, please refer to **Figure 2**. The focused person is shown in the centre. The next circle shows the circle of intimacy (shown in blue), these are the people closest to the person, people they could not think of living without. They are usually the person's family, but also include partners or lovers. The next circle is the circle of friendship (shown in dark green). These are people who are their best friends. People on the periphery of the circle are usually professionals and service providers, club members or work colleagues. These make up the circle of participation (shown in lime green). Sometimes a further circle is included called the circle of exchange. This includes people who are paid for services, for example milkman, or dentist. This has not been

included because Keith does not have it in his relationship map. That is another important principle in person centred planning. Plans that are based on individual needs and wishes. Planning in this way often leads to the adaption of person centred planning tools to specifically meet the individuals wishes, as in this case.

Figure 2. Illustration of the Relationship Map or doughnut.



Adapted from *Circles of Support*, (Falvey, Forest et al. 2003), pg 6.

In order to change people's lifestyles in a person centred way it is vital to have a common set of values and principles (Smull and Sanderson 2004). Many of these are encompassed within the process of person centred planning. People with learning disabilities must be supported under the same principles of community inclusion as any other citizen. It is important to listen and respond in a positive and pro-active way to the needs, wishes and dreams of the individual. Services should not be provided in segregated settings, but alongside non-disabled citizens in the

community at large (Barron 1989; Jahoda and Markova 2004). Services can meet needs best in a collaborative and joint commissioned approach across health, education and adult social care. Person centred plans and their outcomes should be utilised to plan future services, and innovative new ways of provision developed (McIntosh and Whittaker 2000). In order for this approach to succeed it is essential that policy reflects not just values and attitudes, but actively promotes the principles through moral and civil legislation.

THE POLICY CONTEXT

Government policy has a profound effect on the setting of standards, values and attitudes, and informing professional practice and research. State apparatuses also shape the ideological context individuals, and the state function in (Althusser 1984). It is very important that policy should include the ideological and political values and attitudes, the Government expects its people to uphold.

The White Paper “Valuing People” was published in 2001. To many this was viewed as the most influential policy document ever produced for learning disability services (Forbat 2006) . It encapsulated many of the then labour government’s main aims for the National Health Service. It set out a new model for service provision for the twenty first century. This put locally based professionals in control of service provision, working in partnership with people using the service. It sought to guarantee excellent services and best practice delivered to where patients live. It also replaced competition and the internal market, with co-operation and developing centres of excellence, and consistent locally based, efficient services.(Baker 2000).

Valuing People was produced in consultation with people with learning disabilities, their families and carers. It very clearly set out its principles and values

some of which were are follows (Department of Health 2001). Firstly, it supported rights both legal and civil. People with learning disabilities have the same legal and civil rights as any other citizen, and the Government will challenge any form of discrimination, ensuring individuals have the full protection of the law if necessary. Secondly, independence should be promoted particularly by public services. This does not mean failing to act or provide for individual needs based on what services have available, or think people need. It requires providing a variety of choices for an individual based on their own needs and wishes. Thirdly, it emphasised the principles of choice and control. People with learning disabilities should have a say in how they wish to live their lives, and their views must be listened to and acted upon. This includes providing a variety of options for individuals related to where they wish to live, work, and who looks after them. People with severe and profound disabilities should be assisted to make choices with the use of the right support and help including advocacy, and utilising a range of communication strategies to enable this to happen (Spooner and Millard 1999). Finally, and perhaps importantly, inclusion in the community in which they live. This means enabling people to use mainstream services. Also the facilities and activities everyone else can access as citizens, for example use of public transport, or public entertainment/recreational facilities.

There is also a whole chapter devoted to person centred planning. Chapter four clearly emphasises that person centred planning, and a person centred approach to planning means that services are centred on the individual. Account should be taken of the person's wishes and aspirations, and the process is a method of reflecting the needs and preferences of the person. Since person centred planning was seen as a priority the Government sought to direct funding via the newly

established Learning Disability Development Fund, and its progress was to be closely monitored.

The Government issued supplementary guidance to Partnership Boards in the form of a document aimed at implementing person centred planning (Department of Health 2003). This contained detailed information on the different models of person centred planning, how to implement training, and where to obtain resources and further information. It was hoped that this would be the beginnings of a new era, not just in learning disability services, but in the National Health Service generally. An organisation which encapsulated all the principles in the recent legislation, and one which reflected all the Governments political aspirations to bring local communities together, provide locally based high quality services, and bring to an end competition with the private sector, and development of the internal market in the provision of human services (Walker 1993) . A new White Paper was introduced Our Health, Our Care, Our Say: A New Direction For Community Services, to support these ambitions (Department of Health 2006). It also enabled not only a move towards greater choice and control for service users, but also set the scene towards promoting citizenship.

Unfortunately, early in 2007 an investigation was conducted following a number of enquiries into learning disability services, and found significant failings in a number of services (Healthcare Commission 2007). This investigation covered 638 learning disability services, in 17 Trusts and 17 services that were not part of the National Health Service. They found serious failings in six services, and took immediate action. These concerned the quality of care and lack of support for staff,

from the organisations concerned. Even the services that were better in the audit, were not as good as they should have been. There were particular problems in residential and hospital campuses. Here individuals were unable to make choices regarding activities, and do the things they wanted to. Services were not doing enough to safeguard vulnerable adults. There was evidence that many services relied on the use of additional, or as required medication, to control challenging behaviour. There was insufficient quality checking of services from commissioners. There was also, little or no involvement of people with learning disabilities, families or independent advocates. Care plans were out of date, and people did not understand them. Staff often lacked basic training, and support systems. Many services were being run on institutionalised models of care. Individuals were not involved in planning their care and they did not choose who they lived with, or where they lived. There were insufficient numbers of staff to meet people's needs, and an over reliance on temporary staff. Too many people were still living in NHS provision, and this had a closure deadline of 2003. Clearly the new legislation and in particular Valuing People was proving ineffective. This is a view supported by (Dowling, Manthorpe et al. 2007) in their comprehensive review of person centred based policies and practice .

As a response to the findings of the investigation a green paper was issued Valuing People Now (Department of Health 2007). Learning Disability Partnership Boards in particular were tasked with implementing its recommendations. This document had one main priority. That was to ensure Valuing People happens in the following three years, with particular emphasis on the personalisation of services. This emphasised the need for people having more choice and control in their lives;

and the introduction of self-directed support and funding to enable this to take place (Tyson 2005). It also sought to improve what people do during the day and evenings, and to increase the number of people having paid work (Bell 2005). It also aspired to enable people to have more choice over where and whom they live with, and finally ensure equitable and high quality healthcare for everyone. The paper sought to ensure that changes occurred following a review of National Health Service and Social Care performance processes. These required the National Health Service, and Adult Social Care to compile evidence based joint strategic needs assessments that truly reflected local needs. Finally Learning Disability Partnership Boards must ensure that the main priorities are implemented. Also they must provide evidence on a yearly basis of progress, producing a public report on their findings.

Person centred planning is specifically highlighted as the way of meeting individual need and transforming services. However, some authors are rather sceptical about the Green Paper. They are particularly guarded about the influence of Partnership Boards. Since they are not statutory bodies they are not able to make decisions regarding the use of public monies since they have no legal powers (Fyson and Ward 2005) .

The Winterbourne View Investigation which took place following an undercover investigation by the BBC Panorama programme showed that people with learning disabilities were criminally abused (Department of Health 2012). This was a private specialist treatment facility for people with learning disabilities and behaviours that challenge others, as well as those with personality disorders, mental health problems and what has been described as, forensic offending behaviour. As a result of the physical and emotional abuse uncovered the facility was closed down, the

people moved to more suitable accommodation, and a number of staff were convicted following police investigations. The investigation showed poor care models and standards of care, inappropriate placements, people staying there too long and being sent a long way from their homes and relatives, and overuse of physical intervention. In addition there was poor staff training and a clear management failure (Department of Health 2012). One of the major recommendations was that people with learning disabilities and other vulnerable groups receive personalised, local high quality services. Good practice examples were issued with a whole section devoted to person centred planning. This aimed to ensure that individuals and those that know them best were involved in planning their care, emphasising that people must be at the centre of any person centred planning that took place (Department of Health 2012).

The Health and Social Care Act (HM Government 2012), which was originally released as a bill sought to further modernise services providing a high quality, world class National Health Service. It recognised that there was a rising demand for services in that people were living longer, but that treatment costs were also rising due to an aging population with increasingly long term conditions, for example dementia. The Conservative Government was now in power and faced a huge financial deficit. The Government had ring-fenced public spending for essential services. However, it recognised that there was a need for considerable savings including within the National Health Service. In order to increase efficiency, responsiveness, and accountability it introduced clinically led commissioning via an National Health Service Commissioning Board. New Clinical Commissioning Groups will directly commission services for the populations they serve. General

Practitioners would take the lead role in this initiative. It established Monitor as an organisation to oversee patient's rights and ensure they were free to choose what services best met their needs. These could be chosen from a variety of providers from statutory services, for example the National Health Service, or voluntary, private and charitable services. It also set up Health Watch to ensure patient involvement was represented throughout the NHS. The act also sought to streamline services, and remove unnecessary layers of managerial bureaucracy. Adult Social Care were already responsible for ensuring co-ordination and inspection of all local services. Also ensuring people could choose where to go for the services they needed, by having a personal budget. They could also choose to have a direct payment option, where they received the budget, and paid their service providers direct (H M Government 2007). The Act reinforced the role for Local Authorities. Care managers in adult care services were responsible for assessing individual's needs, and helping them develop a personal support plan. It was hoped that this would enable individuals including people with learning disabilities, their families and carers to have greater choice, and control, over how they lived their lives. As such it represents a shift in Government policy from personalisation to social inclusion, and a step towards building social capital (Duffy 2010).

In 2014 The Care Act was passed aiming to provide care and support guidance (H M Government 2014). It is a very comprehensive document that specifically itemises and explains all the past legislation. It specifically seeks to promote wellbeing which it recognises is a very broad remit. However, it highlights personal dignity, physical , emotional and mental wellbeing, individual participation and control over how people live their life, and recognition of the individual's

contribution to society. It assumes that the individual is best placed to judge their own wellbeing, unless they lack the capacity to do so. It promotes independence, suggests preventing or delaying meeting an individual's care or support needs if unacceptable. It also seeks to assist an individual to access "preventative services". These are described as those services that assist the person to stay in their own home, and maintain their independence, or caring role. It places a specific duty on Local Authorities to provide information and advice relating to care and support, in a variety of formats. Thus enabling people with a variety of needs easy access to the services they need. They also have a duty to maintain, establish new services, and co-ordinate all local services, including working closely with the NHS. It also specifically stresses that there is also a duty to maintain services and safeguard vulnerable adults, which include some people with learning disability. There is a section that outlines consideration of the person's strengths and capacities, which is very person centred. It specifically highlights that in assessing the individual's needs consideration should be given to all of their needs, not just those requiring care and support. It mentions encouraging people to use their gifts and strengths, and a need to develop individual capacities to encourage social integration. It also recognises the importance of the individual's families, carers or friends. Also that people should be considered in the context of their individual networks. Whilst the Act seeks to protect people from abuse or neglect, it also attempts to do this in a way that is, the least restrictive of their individual rights and freedoms.

It is refreshing to find a policy document that stresses the importance of values and attitudes in order to provide people with appropriate person centred care and support. Although not specifically mentioned it also illustrates how person

centred planning, personalisation, and increased citizenship could be used to support these practices. Some authors suggest that the publication of policy documents in this way is “toxic” in that they reinforce the cultures of punishment, control or protection. Indeed the term personalisation becomes not a reason for embracing involvement, citizenship and individuality, but rather a way of depersonalising the individual into an object on which others have to act (Nunkoosing and Haydon-Laurelut 2013) . I can appreciate it has a resonance with the “thingification” of the world, ignoring people and their individual experiences. The emphasis on protecting the vulnerable can also be seen denying the fundamental nature of human beings, their relationship with people (Goodley, Lawthom et al. 2004). However, people with learning disabilities are often vulnerable to exploitation and abuse as has been evidenced in the various investigations cited in this study. This is particularly evident when people are problematised as damaged, represented as “other”, socially isolated, institutionalised, and excluded from their own social networks (Robinson and Chenoweth 2011).

It is hoped that the new Care Act will lead to new ways of working across services and boundaries ensuring all people, including those with learning disabilities are offered choice, control and a very real involvement in how they choose to live their lives (Cole and Lloyd 2005; Department of Health 2010).

THE ESSENTIAL PRINCIPLES OF PERSON CENTRED PLANNING

The main assumption proposed is that person centred planning promotes personal growth and autonomy of individuals, encourages social inclusion and citizenship. There is also a suggestion that it promotes self- determination by the use of dreams, desires, and the North Star (Pearpoint, Forest et al. 1993). Although

these are metaphysical and spiritual, they are assumed to form an inherent part of any form of person centred planning.

The provision of evidence to support these assumptions are rather more challenging, particularly if one considers scientific or empirical explanations. There has only been one large scale evaluation of person centred planning in the United Kingdom (Robertson, Emerson et al. 2005). This was carried out on 93 people most of whom lived in various sites ranging from psychiatric hospitals to supported living arrangements. A battery of tests, assessments and interviews were administered. The results indicated that for 52% of individuals there was an increase in the size of social networks, 40% increase in contact with friends, 30% increase in the number of community based activities and people were twice as likely to have more choice and control over their lives. In addition it was found that the cost of providing this approach was neutral in comparison with the overall costs of care provision. The most enlightening results were the narrative accounts of the participants; many did indeed find the process empowering, enjoyable, and liberating. However, a few found the process difficult, worrying and were concerned they would say the wrong things. This is hardly surprising when one considers many had never had the option before of being involved in planning how they wished to live their lives, because they had received institutionalised care for many years, (Pitonyak 2002; Beart 2005). Personal narrative accounts can provide very real insight into how a process works, and is particularly useful with person centred planning approaches since the whole direction is to focus on the person, their experiences, feelings and aspirations (Atkinson and Williams 1990; Hingsburger 2000). It is suggested that increasingly individual voices will have an increasing

influence on the personalisation agenda, with a particular emphasis on shaping the way services are delivered.

THE PERSONALISATION AGENDA

Person centred planning and person centred approaches have a role also to play in assisting services to develop and grow. A number of lessons have already been learned regarding its implementation. These include effective leadership by individuals who fully understand person centred planning and person centred approaches. Training and supporting staff in these key areas and promoting a person centred culture at all levels of the service. Also ensuring that the organisational culture has person centeredness embedded as key values for all employees (Department of Health 2010).

The implementation of personalisation remains problematic. One area of concern is the link between it, person centred planning and the process of care planning and service commissioning. With the increasing emphasis on user engagement and involvement at each stage of service provision, there is a need to take into consideration the choices of people with learning disabilities. Some individuals may choose to obtain services from within existing provision. Others may wish to take control of their budget and life, via direct payments purchasing flexible and innovative services from a variety of providers. Some of these may be in existing provision, others may exist in the community generally, and some may be new and need to be created. It is suggested that person centred planning would be the best method to ensure the persons requirements for services are met (Needham

2011). This requires a new way of thinking in order to create individualised creative solutions, and this will require responsive services, and new ways of working.

Unfortunately, most local authorities use a model based on financial control and effective administration. This usually requires the person to be assessed usually by a care manager meeting with the person and their family. They then require a Resource Allocation System (R.A.S) form to be completed. This defines how much money the person will receive. Ideally local authority staff should work with the individual to develop the support plan. This clearly indicates how the money will be spent to meet the persons needs (Mansell and Beadle-Brown 2005). In Keith's case he was given a pro-forma to complete which had a few pictures and symbols indicating his support needs for example, health needs, care needs, and activities he would like to do. The support plan replaced previous care plans and Individual programme plans. Keith objected to being sent a pro-forma, and returned the document following discussion with his circle. A person centred support plan was produced using In Controls seven steps to support (these are outlined on pg 68). Keith had to indicate how the allocated money was going to be spent, and the session hours he needed to enable him to achieve his wishes. A care manager/social worker costed the sessions, and the document was sent to the local authority for approval. Services could only be commissioned by approved service provider, severely limiting his choice. This is not uncommon, similar difficulties were reported by Emerson and Hatton (2008). A particular difficulty appears to be resolving the Local Authority requirements for political, fiscal and administrative compliance and transparency, with the service users need for personalised services, and being in control of the decision making process. The introduction of direct

payments and increased civil power and activism on the part of people with learning disabilities post Valuing People Now, has further increased this tension. There are particular concerns with regard to care management, and how it fits with person centred planning (Cambridge, Carpenter et al. 2005). The authors note a number of difficulties cited in a twelve year study of learning disability and mental health services: Firstly care management has been underfunded this is even more marked with the current financial difficulties faced by most Local Authorities to make 25% cost saving year in year.

Secondly, although a number of “personalised” services had been developed they were generally based on the original care planning arrangements of referral, screening for service eligibility, assessment, care planning and monitoring, re-assessment, and finally case closure. Although the plans were variously named as individual service plans, individual programme plans, person centred care plans they were administratively driven, professionally lead and often become a paper exercise.

Thirdly, there was a lack of commitment from senior managers to support staff to enable achievement of the personalisation agenda and to support staff to enable services users to access the full range of care and service options available to them .This was particularly evident in the case of people with behaviours that challenge, or individuals with profound learning disabilities.

Cambridge et al (2005) call for an integration of care management with person centred planning, since the later is viewed as the vehicle to support personalisation. They suggest information from care management should inform person centred planning, but not stifle or constrain it. Likewise some information is required from person centred planning to enable service development, and personalised care planning.

Some organisations incorporate plans as a key part of strategic service development. By starting with individual plans and recognising they are not audit reports, or administrative check lists, they represent individual voices stating how people would like to live their lives. New and creative solutions can be found to provide services. These are not based, or limited by existing available resources, or current service configuration (Cole and Lloyd 2005).

It is also important to involve people with learning disabilities, their families and carers throughout the gathering of information, and new developments. Increasingly informal planning networks including family and friends are viewed as the most appropriate way of ensuring choice, power and control, so essential to effective person centred planning, resides with the person (Duffy 2011) .

It should be recognised that not everyone is an enthusiastic supporter of personalisation or person centred planning. Some link it with a neo-liberal agenda on the part of the Government. Whilst they accept that the move towards citizenship and control over the way people are supported is an equitable right for everyone. There remain concerns regarding the way market forces have appeared in the field of health and social care. Also the political aim is not increased free choice for citizens, but welfare savings for the Government. Individuals question that there is sufficient variety in services for people to choose. Also if people want that responsibility, or have the ability to choose from different providers (Rose 1999; Lymbery 2014).

Some view person centred planning in particular as just another technology aimed at producing personalisation. It results in limiting the range of everyday activities in which people can engage, particularly for those individual that require

supported decision making (Dunn, Clare et al. 2010). It is interesting to note that this study was conducted in a residential care home for people with learning disabilities. Most of the decision making was made by support workers, not the individuals themselves. The findings suggest that developing partnerships with the person, support workers, relatives and others involved with the individual was a solution, in short person centred planning, or at the least a personalised approach.

The concepts of choice, citizenship, control and social inclusion are essential components to both personalisation and person centred planning. It is imperative that no-one has to have a plan. It is a matter of individual choice (Goodey 2015). In order to enable strategic developments, new ways of information sharing will need to be developed, particularly for those who choose not to have a plan (National Disability Authority 2004). Sharing needs to take place across agencies, organisations and service boundaries to produce a unified cohesive approach. Hopefully with the introduction of new commissioning groups for services, and the recommendation that people are put at the centre of all service provision (HM Government 2012), such a collective approach can be achieved.

CHAPTER 2 METHODOLOGY

INTRODUCTION

The main research question of this study is: How authentic is person centred planning as a method of life planning for people with learning disabilities? The study focuses on person centred planning, and circles of support and explores the processes, relationships, methods used by Keith's circle of support to plan his life. In particular it seeks to focus on the existential "essence" representing the phenomenological "truth" of the experience for the individual circle members, in the way the circle plans. As such it poses a number of discrete epistemological questions related to the experience of circle members:

- How do all circle members experience the process of person centred planning and what underlying meanings/ processes are operating?
- What are their expectations in terms of experience, and outcomes for themselves, and most importantly for the person they are supporting?
- How do members' experiences and expectations differ, and do they differ from those of the person they are planning with?

In this chapter I will explain and justify the research design, the membership of the circle of support, and their relationships. Also the choice of research methods, and methodological paradigms. The chapter also encompasses the approach to obtaining and gaining access to data, data analysis, including the structure for analysis, and how themes developed. The procedural methods adopted for this study and ethical considerations are also described. This includes applying to ethical

committees for approval, and the researcher's experience of this process. The methodological journey travelled is particularly significant since this has much in common with how person centred planning is described and experienced (Falvey, Forest et al. 2003).

PARADIGMS AND RESEARCH APPROACH

A number of interpretive and inclusive approaches have been investigated. These relate to the philosophical positions taken within this study. Fundamentally the philosophical/theoretical approach is phenomenological, with a bias towards metaphysical explanations. There is a particular emphasis on Sartrean existentialism (further details of these are outlined in the previous literature review). The reasons for doing so relate to person centred planning being grounded within a foundation of humanism (Sartre 2007), and discourses related to personhood and ethical practice (Levinas 2001; Sanchez 2007), an explanation will be given in the following section.

It was important to choose an approach that related to the ethical/emancipatory stance taken in the study's philosophical and theoretical positioning. Also one which supported the assumed position that person centred planning is inclusive, ethically driven and grounded within a value base centred on community integration, the promotion of individual autonomy, and active and careful listening to the individual's wishes, desires and needs. The investigation of authenticity as it relates to person centred planning in this study is directly connected to examining these issues.

In particular, an interpretative paradigm was chosen, and a qualitative research approach adopted because this requires the researcher to be inductive,

creative and responsive to the phenomenon being studied (Mayan 2009). Of particular interest in this study were the feelings, views and relationships of the participants in the circle of support. How do they experience life as a group and as individuals working within a particular group, field or culture? How do they as a collective help the person they have chosen to assist? Is the experience different for individual members (including the focussed person)? I preferred to develop a study based on the examination of naturally occurring phenomena within a circle of support. Within this I chose to use an intuitive approach, utilising a range of theoretical/methodological approaches based on what naturally occurs (Hammersley 1992). The study was also concerned with exploring authenticity in person centred planning, as a result of the individual's lived experience. This is reflected with regard to their experience within the circle of support, and in their everyday life (Silverman 2003). Indeed a particular focus of person centred planning should be a recognition of the individual person's voice. Also, an acknowledgement that the person, and their circle of support are experts in their own right (Needham 2011). It was important that the study engaged with the individuals in the circle, so they felt part of the research process and not passive recipients or subjects to be experimented on (Mansell and Beadle-Brown 2005). Since there is also an interest in what underlying meanings or processes are operating, a study that focussed on measurable and definable variables would be inappropriate. This is because having a study focussed in this manner can lead to the loss of naturally occurring phenomenon within the data, and stifle original and creative thinking about the field of study (Glaser and Strauss 1967).

This study has also rejected within the literature review any scientific rationalisation related to the care and treatment of people with learning disability. A scientific

positivist approach would have been unsuitable in this particular study (Durkenheim 1982). It is important to reflect on the methodological journey taken, since any research study should involve a degree of reflection around the research question. This results in a process of constant refinement, which is an essential component of good qualitative research. The researcher is not just interested in what is, but also what may be, and also what could be based on some “A priori” knowledge of the subject (in this case person centred planning) (Huberman and Miles 2002) .

METHODOLOGICAL JOURNEY AND APPROACHES

I have opted to draw on a number of different methodological approaches, rather than choose a particular method. The reason is that there was great difficulty in finding an approach that fitted neatly with the philosophical/theoretical positioning described within the literature review. However, the framing of this research is directly related to phenomenology and existentialism, since this study is concerned with how people in the circle experience the meetings and how this contributes to a better understanding of person centred planning, and of supporting people with learning disabilities (Firestone 1987; Huberman and Miles 2002).

The use of narrative enquiry was initially considered as a suitable approach (Holstein and Gubrium 1995). Narrative accounts can provide descriptive illustrations of reality for the individual regarding their own quality of life. It is proposed that narrative enquiry can also provide insight into an individual’s life experienced as a result of person centred planning, and other inclusive ways of supporting people with learning disabilities (Atkinson and Williams 1990). Such accounts provide an explanation that promotes individual autonomy and agency, and respect for the individual (Brechin and Walmsley 1989), whilst also recognising that

they interact with and shape their environments (Garrick 1999). The process involves carrying out research with people, rather than on them (Blumer 1955). In this way the “truth” of personal narratives is to an extent the result of individual experiences, and the world that shapes and informs them (Riessman 1993).

I particularly valued the research process used in narrative enquiry since it is inclusive, autobiographical and empowering of the individual , and requires mutual empathy and developing a trusting relationship between the researcher who attends to what is said, and the individual who tells their storey (Nierse and Abma 2011). Although the inclusive nature of narrative inquiry was admired, the emphasis on the grammatical content of what was said was not. In particular the minutiae relating to individual words and phrases, and the emphasis on word expression was thought to be inappropriate to this study. This study is concerned with the authenticity of person centred planning as an approach, and how individuals in the circle experience, and relate their experience to the process of planning in the circle. Also of relevance is the individual and group experience of what occurs, and how they later recall that experience. However, what was relevant was the content of individual narratives. I thought this could be utilised throughout data analysis, during the transcription of individual interviews. A further search was required for a method that focussed on interactions with particular emphasis on the individuals involved, and how they related to each other within the circle meeting. This also emphasised the ethical and emancipatory positions taken in this study of promoting active participation, individual involvement, and the development of personhood.

ETHNOGRAPHIC APPROACHES.

The study was better situated to an ethnographic approach (Jacob 1987). Since the study was concerned with answering questions related to how does person centred planning promote individual empowerment and self determination? What relationships are formed with local communities? What conscious and other processes operate? and how do these “mentalistic” phenomena shape individual, and group behaviour (Goodenough 1971; Hammersley 2000).

There are some who view such metaphysical observations as unscientific, and suggest that it is only by studying patterns of observable behaviour that true insight can be gained (Harris 1968; Firestone 1987). However, an approach based around ethnographic principles appeared to fit this study. Garfinkel (1967) concluded that ethnography concerned itself with the behaviour of people in the form of what he describes as “indexical expressions”. These are produced as individuals go about their everyday lives. It has much in common with symbolic interactionism and dramaturgical psychology described in the literature review (Blumer 1980; Goffman 1990). Ethnographers are interested in studying all the common sense behaviour and beliefs within a given social group, and in particular, to examine and try to explain experiences individuals have in such settings (Coulon 1995). It is about immersing oneself in the culture of investigation, and utilising a variety of methods to provide insight of what is the lived reality. Since it is also a method that involves active participation and involvement of those within the culture studied,(in this case the person centred planning circle of support) in many ways it is suitable for people with learning disabilities to participate. These people have often had to endure practices of exclusion, negative labelling and welfare and professional paternalism

(Goodley, Lawthom et al. 2004). So any approach that promotes involvement, interaction, and active contribution for people with learning disabilities is most welcome. The emphasis on describing the lived experience of the circle of support, and the subsequent reflection on what was observable and reportable (Garfinkel 1967) was a methodological approach that resonated with the aims of this study.

VISUAL ETHNOGRAPHY

The final methodological approach considered was visual ethnography. This approach is one which represents a process of creating and representing knowledge about how a society or culture functions. It achieves this by the use of visual material such as pictures, photographs film, video or other visual representations (Emmison and Smith 2000). As well as representing what can be seen, it can also represent the underlying meaning within a culture, and what individuals think and feel. Castaneda (2006) considers ethnography as a form of visual invisible theatre. In particular, fieldwork is viewed in terms of the researcher immersing themselves in a culture, and interpreting and describing all the interactions or performances made by the “actors”, or cultural participants. In this way the subjective interactions (researcher’s interpretation of the performance), in addition to surface interactions (what can be seen and observed) are commented and described using symbolic, descriptive and interpretive approaches. This results in ethnographic fieldwork that is situated within an approach of “being in”, and interpreting the culture. As opposed to “observing what is seen” through observational data gathering and reporting. This approach to ethnography builds on the work of Bateson and Mead described by (Ness 2008). Bateson and Mead (1942) spent a number of years observing Balinese culture. Initially they reported and were interested in the gestural interactions they observed,

but through the use of photo and film eventually realised that the gestures communicated in very subtle ways not just non verbal meaning, but what can only be described as phenomenological meanings embedded within Balinese culture. These included the use of finger and eye movements, particular ways of walking and a variety of facial gestures. These “performances” were utilised in ritual dances at specific gatherings, for example funerals, but also as a basis for social interaction, especially in relation to mark the differences in status between individuals. For example, the bodily positions and gestures were different between woman and men, but the elders (only men), used different positions and gestures to highlight their status. It was one of the first occasions that film and photographs had been used in this way within anthropological research. It also represented a methodology that could be useful in this study.

Video is a medium that can enable people with learning disabilities to express their views and experiences, and have them accurately captured very easily. It is also a method that can enable society to become aware of people with learning disabilities, through the promotion of social presence (Goodley and Moore 2000; Rojas 2011). Video and photographs in particular are increasingly used not just as representations of the sociological field or culture in which they were taken, but also as a way of representing active elements of that culture (Pink 2005). Pink (2008) also views visual ethnography as a place making event , and one in which the researcher is an active participant. Not only is the researcher seeking to understand the culture but they also need to understand how they are placed within it, and how their being there affects what takes place. This was an important consideration in this study, since I was a member of Keith’s circle of support, and therefore part of

this culture. This is fully explored in the discussion chapter of this study. However, the notion of active participation within a place making event (Keith's circle) had considerable appeal. Visual methodological approaches have a number of critics for a number of reasons.

There is a degree of scepticism regarding the use of visual material in research from ethics committees. They often have concerns regarding its usage on moral and ethical grounds, particularly related to preserving participants anonymity and preventing the disclosure of personal information (Russell 2007; Mayan 2009). There is also the issue of who owns the visual material after the study, and how it is going to be disposed of after the study (Heath, Hindmarsh et al. 2011). This is the reason why this method alone was not used in this study. The NHS ethics committee in particular would not allow the use of any patient identifiable material (this is covered in greater depth in the ethics section of this chapter). There are also some methodological questions regarding the issue of how the visual data is interpreted. Is it the researcher's interpretation? or the people's in the study? or both? Also how accurately does it reflect what is really taking place? (Prosser 1992). Since this study is grounded within a phenomenological framework, I considered that all interpretations were valid. Since they provide insight into the conscious and underlying processes operating, in addition to what can be actually seen from the visual data (Russell 2007).

Although the methodologies described so far include many of the principles encompassed within this study, there was still a need to search for a methodology that fitted holistically, with its theoretical and methodological foundations. It also

needed to enable an analysis of data in a systematic and rigorous way .Discourse analysis was a methodology that was eventually chosen because it fitted with these desired aims and objectives.

DISCOURSE ANALYSIS.

Discourse analysis refers to a range of approaches and theoretical traditions ranging from pure linguistics, social psychology, semiotics and sociology. As such it can appear very confusing. Some authors have clarified the problem by considering discourse analysis as consisting of two main types of academic work (Jaworski and Coupland 2000; Taylor 2013).The first type of work is concerned with the nature of language as represented in the study of linguistics, phonology, morphology and syntax. The emphasis is centred on the content and minutia of language. The second approach is concerned with the study of people, and how social phenomena shapes human behaviour, including the use of language and behaviour (Fairclough 1995). This approach appeared to resonate with the theoretical phenomenological emphasis in this study.

Using this approach the researcher is attempting to understand how the individual experiences and makes sense of their everyday life (Smith, Flowers et al. 2012), and as such is concerned with everyday experience. Also how this is related to the individual's own life world (Husserl 2012). In this study the life world experience relates specifically to Keith's circle of support, but also the life world of the circle members, and how they go about their everyday life. This approach is based on the same principles utilised in person centred planning. At the centre of the circle of support is the person assisted by people they have chosen to try and achieve the life they would aspire to have. The emphasis is on the shared and

individual experience of planning in the circle, but also wider in the context of emancipatory approaches for people with learning disabilities, and supporting self determination. Planning in this manner is thought to be humanistic, interpretative, reflective and life affirming (Mount 2002; O'Brien and Mount 2005).

Discourse analysis can also involve the study of other forms of representation derived from language, this can involve visual material, for example pictures, drawings, photographs, paintings and historical documents (Mills 2004). Mediated discourse analysis is concerned with mediated action, people interacting as a result of social action. It is also concerned with how people develop social practices as a result of their actions and interactions, for example, Keith's circle of support. Some authors describe a social matrix of practice within which mediated action takes place. This leads to the development of communities of practice (Lave and Wenger 1991). These are groups of people who come together to share in a common practice. The emphasis is on learning, and ultimately a change of identity. Individuals enter the community as novices and over time develop expertise, in this way the community develops its own history over time. An individual may be a member of different communities of practice, but the emphasis within each one is on learning, participation, identity and shared action (Scollon 1998). It would appear that many of these qualities are also those stated as required for effective participation in a circle of support (Routledge and Sanderson 2002) .

One of the major debates involved in discourse analysis is the nature of discourse and how this shapes social practice, with regard to individual communities of practice, but also the wider community which involves the action of state

institutions and authority. Fairclough (1993) views all forms of discourse as varieties of social practice. He supports the principles cited in many of the social psychological/symbolic interaction explanations of human interaction (Blumer 1955; Nye 1977; Goffman 1990) cited in the literature review. Discourse and human interaction produce social action that takes place at the individual, group, and wider world level. This interaction is also shaped and constrained by the situations in which individuals and groups find themselves. Individuals shape their own and others interactions, depending on a variety of factors including their current situation, the role they are taking, the expectations of the other participants, societies laws and values, and the culture, institution/situation, where the discourse is occurring (Scollon 1998). Discourse can be seen to contribute to the development of social identity, and the development of an individual view of "self". It also helps to construct social relationships between individuals, and also produces systems of knowledge and belief (Fairclough 1993). Discourse and discourse analysis is viewed as a means of highlighting inequalities, both in terms of individual power and control, but also as a direct consequence of the actions of state institutions. For example, the service eligibility criteria required for people to access NHS learning disability services (Mills 2004). It is viewed as a means for promoting, and highlighting social change as a consequence. As such it supports the views of disability right activists and self advocates (Dearden-Philips and Fountain 2005). Discourse can also effect ideological views. In particular it can influence how people develop systems of meaning that assist them in making sense of their everyday interactions with the world. Some of this will take place in their imaginations philosophically; some will occur in reality, both will affect how they interact socially (Althusser 1984; Macdonell 1986).

It has been suggested that the study of discourse, and discourse analysis is incredibly diverse involving a variety of disciplines ranging from psychology, social science, anthropology, cultural studies and linguistics. In this study the theoretical domains suggested in the literature review include social interaction, individual views of self, culture and social relationships, definitions of authenticity and disability (Van Dijk 1997).

There is also variety in the data collected from individual video elicitation interviews, video of a circle meeting, and person centred planning graphics. The analysis considers the discourses produced from the variety of data collected in this study as reflective, not just as means of communication for the circle of support, but related to the wider issues, of how discourse shapes and influences individual actions and the meanings ascribed. Also the wider context of how they influence the community generally (Van Dijk 1997). The data analysis is interpretative and grounded within the evidence provided from the data collected. Discourse analysis requires the researcher to detect patterns/similarities in the data which allows for the generalisation of data labels based on commonality (Wetherell, Taylor et al. 2001). It must be recognised that although the researcher's analysis is systematic and ordered, it is conducted as the result of obtaining second level information. The researcher is making sense of the person's experience, but only from their account of it (Ricoeur 2004). He suggests the researcher's interpretation takes place at two levels. A hermeneutics' of empathy, and a hermeneutics of suspicion. The former approach attempts to reconstruct the experience as it actually occurs. The latter uses theoretical positions to interpret what is seen. For example, in this study phenomenology and existentialism are utilised within a theoretical position promoting emancipation, personhood and inclusion.

Discourse studies are conducted with small samples and a group with commonality. In this study the commonality is planning with a particular person. Individual narratives are then analysed. Findings and conclusions are suggested and developed. This includes drawing broader conclusions and recommendations as a result of theoretical generalisation. It is also important to recognise that there is also a need to examine “underlying meaning”. Often underlying meanings once expressed, can bring real insight into what is being studied (Sanchez 2007).

A number of methodologies were employed within this study. A modified form of narrative analysis was utilised within an ethnographical approach, which included discourse analysis. The emphasis within the fieldwork and subsequent data analysis centred on the content of individual narratives as a whole, not on the minutiae of words, phrases or stresses on particular words or sentences. The emphasis on “telling the story” of the experience of being a circle member was crucial to gain insight and understanding of the phenomenon taking place within the life world, or culture of Keith’s circle. This view is supported by Mead’s work (Blumer 1966) since it contributes to understanding meaning for an individual, or a group of individuals within a distinct cultural context. It also supports Heidegger’s account of “Dasein” of “being in the moment” (Heidegger 2008). Here human experiences and interactions with others, shape how individuals and groups make sense of their world, and how they develop their own view of themselves and others. The emphasis on telling the story also resulted in the choice of methods chosen during the data collection phase of the study, which will now be described.

VISUAL METHODS

Visual methods, in particular the use of video and audio/visual recordings are very successful when used with people with learning disabilities since they readily engage, enjoy and understand what is taking place when these methods are used (Manning 2009). The “What’s Happening Project” in Glasgow (The Foundation for People with Learning Disabilities 2005), used video diaries to enable young people with learning disabilities and mental health difficulties to communicate their emotions and feelings. An important finding was that the participants displayed feelings and emotions that were not captured during face to face interviews.

Many of the person centred planning methods use pictures, video and photographs to enable full and active participation (Pearpoint, O'Brien et al. 2001; O'Brien and Lovett 2002). Indeed it was a recommendation from the United Kingdom Government that all information for people with learning disabilities should be produced in an accessible format. This could include the use of easy to read words and pictures, video, audio tape or DVDs (Department of Health 2001). It could also involve the use of edited or specifically manipulated photos, pictures videos or symbols. Indeed a personalised approach is very applicable for many individuals since the purpose is to enable greater understanding and enable communication, choice and control. This is particularly advocated for people with autistic spectrum conditions (MENCAP 2000; Department of Health 2009).

However, there is some debate regarding the manipulation of the visual material used in this method of research. Some authors consider editing is a form of montage production, and is valid since it is used consistently in film making as a

technique (Rose 2008). Others also advocate editing, citing that the authenticity of the photograph is not invalidated but enhanced. This is because the image does not represent scientific reflections of the world studied, but simply captures moments in time. (Prosser 1998; Winston 2006). Others remain very critical regarding the use of digitally produced photographic material. Baudrillard in particular viewed the manipulation of digital images as an alteration of the object from the real world, to the realm of the digital and artificial. The photograph is viewed by him as capturing a moment in time which encapsulates forever a part of the real world, it has a singular presence but this is altered when a digital camera is used. When software is used instead of the human eye the process is no longer photography, but becomes digital manipulation (Baudrillard 2009). This is an understandable suggestion in part, but even “real” photographs are manipulated during the developing process using different chemicals to enhance the image. This too alters the moment in time. For this reason any digital manipulation of images have been avoided in this study, with the exception of removing names, or other confidential information participants did not wish included. Three visual methods were used in this study. Photographs of Keith’s person centred planning graphics, a video of the circle meeting, and finally video-elicitation interviews.

PHOTOGRAPHS OF KEITH’S PERSON CENTRED PLANNING GRAPHICS (GRAPHIC/DOCUMENTARY DATA)

Keith had already developed a person centred plan which consisted of a number of graphic representations of how he wished to live his life. He gave permission for these to be photographed. Graphic representations of person centred plans are often viewed as the most appropriate form of representing the individual’s

life plan. Indeed they are a pre-requisite for P.A.T.H. and personal futures planning. By planning with graphics in colour it is asserted by the authors that different parts of the brain are activated helping individuals think differently, and more creatively (Pearpoint, O'Brien et al. 2001). Personal futures planning relies on pictures, symbols, collages, and other art work to assist individuals who often lack literacy skills to remember and recall their art creations, and the ideas they represent. The creative process itself assists in building relationships and connections with others, and promotes self-esteem, and a valued identity (Mount 2000). This process has been used successfully to assist people with learning disabilities to develop community connections through collaborative art projects in New York, for example the Pathfinders project which enables people with learning disabilities to build connections with their local communities (Mount and O'Brien 2002).

Photographs were taken of seven of Keith's person centred planning graphics. These were his relationship map, two sections of his P.A.T.H, his dreams, his interests and personal qualities, what people like and admire about him, and his gifts and worries (from his perspective). The only editing that took place was the removal of individual names, to preserve anonymity (Please see **Appendix 5**).

VIDEO OF CIRCLE MEETING

I decided that I would video a full circle meeting. This would produce a verite' video of the meeting. I could then analyse a transcription of the meeting using thematic analysis. Prosser (1998) advocates the use of verite' filming since it enables the researcher to combine participation, and observation of an ethnographic group. It also enables the researcher to gather a rich source of visual and audio

data, and it was hoped that this would provide insight into the phenomenon operating within the group, including any individual and underlying processes. (These visual techniques were used by Mead as described by (Ness 2008) with great effect to document photographically the rituals and behaviours of Balinese culture). However, (Harper 2003) describes how such studies not only record descriptively and observationally, but allow the generation of new theoretical insights into what is actually taking place on an individual and group level.

VIDEO ELICITATION

The use of video elicitation techniques is a developing method of qualitative enquiry, but I decided to use it as it has been extensively used with individuals in the medical field with great success, to promote patient views as opposed to those of professionals (Arborelius and Timpka 1991; Henry, Forman et al. 2011). The method has also has been successful with people in care, especially those with developmental disabilities (Calderhead 1981; Chou and Lee 2002), although its use in this field has been very limited to date.

The basic principle of this approach is to use a video of an interaction, and play it back to participants so that a response to what was seen and heard can then be analysed. It has been particularly useful in the elicitation of feelings, emotions, and service user views. It was proposed that it could be used in this study as a means of unlocking any “underlying meanings” operating within the circle. According to Sartre such meanings are just as important in defining how individuals see themselves, and the contexts in which they find themselves (Sartre 2008). I am particularly interested in how the circle members view themselves, and their work in

supporting Keith. Also what do they feel about this? What feelings does this experience unlock? How does this affect or influence person centred planning within, and outside of the circle. This approach was used by (Gauntlett and Holzwarth 2006). They view the use of visual methods in a similar way. It is an empowering method that enables people to talk about their identities, experiences and feelings. The key is the reflection by the individual to the viewing of the visual material, in this case a video. It would appear that participants have three types of experience. Firstly they recall thoughts, beliefs and emotions that took place during the event. Secondly, they actually relive the interaction when they see themselves played back on the video, and thirdly they reflect back on how they felt, what they experienced, and what they thought (Henry and Fetters 2012). The emphasis in using this method has been on understanding the individual conscious and unconscious processes via individual recall and self- reporting. How do these influence their thoughts, feelings and emotions when they see and recall the video of the event? Also how does this influence how they view themselves and others? with regard to the world of the circle, and society generally (Bryan and Sherman 1980; Fuste'- Herrmann, Silliman et al. 2006; Rymes 2013). I selected three clips from the full video of the circle of support meeting. Each clip contained interactions, between the group participants, that had the possibility to yield interesting conversational data when showed to group members (details of these are described later in this chapter). These became the video elicitation used during the interviews.

THE CIRCLE OF SUPPORT AND INITIAL PROCEDURES

The circle group was in part self- selecting, in that the researcher was working as a member of a number of different person centred planning circles of

support. However, the National Health Service Ethics Committee required that each group was individually contacted in writing to seek permission for the study. The first group contacted was Keith's group, and all members readily agreed to participate. Keith required some additional information and support. My research notes indicated that he was particularly concerned that any video material was not shared with other professionals. We agreed he would retain the original copies of the video of his meeting, and audio interviews, but not copies of the other participants' interviews, since this would breach their confidentiality. Once he received this reassurance he gave permission to participate. He suggested that I came to the next circle meeting to video, and obtain formal consent from all members. Each member was shown a copy of the information sheet produced for the study (copies are included in **Appendix 2**), and I explained they could opt out at any time. All signed consent forms and retained a copy, Susan (Keith's girlfriend) used an easy to read version, and it was explained to her what she was agreeing to participating (please see **Appendix 3**). The group agreed that the rules for meetings (agreed with another self advocacy group) were satisfactory and did not require amending. Keith also had his own copy of rules for his meetings. These are included in **Appendix 4**. The meeting was videoed, and subsequently individuals were contacted to arrange the individual video elicitation interviews.

All the easy to read and understand information was produced using local guidelines formulated in conjunction with the Learning Disability Partnership Board. This body is drawn from a variety of stakeholders. It includes people with learning disabilities, their carers, service providers and charitable organisations. The Board has overall responsibility to ensure services are high quality, locally based and

produced with people with a learning disability. Naturally a communication strategy was developed for all written material produced by, and for people with a learning disability. This requires information to be produced with clear and simple text. On a yellow background, and clear typeface e.g. Ariel 12 point or higher. Images such as photos and drawing are used to support the text (MENCAP 2000).

KEITH'S CIRCLE OF SUPPORT GROUP COMPOSITION

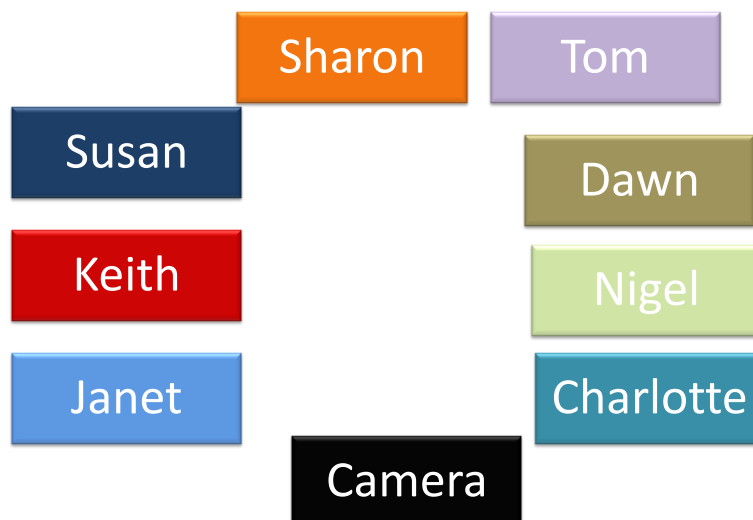
Keith's group had been working together for three years, and I had been working initially as a peer facilitator. This was a role created by The Foundation of Learning Disabilities to enable newly trained facilitators to be guided by an experienced peer. Keith and Charlotte were originally facilitating jointly, and asked me to become their peer facilitator. I later became a group member on Keith's invitation. Keith at the time of the study facilitated his own group. Group members assist him when required, a process which still continues. Five of the group are trained person centred planning facilitators, and all have been involved in providing person centred planning training. Susan, his girlfriend also has expertise as a health trainer. **Table 1** outlines the individuals, their background, and their relationship to Keith. All names have been anonymised apart from my own.

Table 1. The Members of Keith's Circle.

Person	Relationship	Background	Profession
Keith	Focussed Person	Learning disability service user .	Trainer, self advocate.
Susan	Keith's irlfriend	Learning disability service user.	Trainer, self advocate.
Charlotte	Friend	Retired, married to Nigel.	Learning Disability occupational therapist.
Nigel	Friend	Semi- retired married to Charlotte.	Architect.
Dawn	Co- worker/friend	Manages learning disability educators.	Learning disability nurse.
Sharon	Keith's mother.	Carer for Keith and married to Tom.	Carer.
Tom	Keith's father.	Retired married to Sharon.	Retired policeman.
Janet	Friend/ health facilitator.	Member of learning disability team.	Learning disability nurse.
Chris	Friend.	Retired health worker.	Learning disability nurse.

I used a Sony handycam video camera on a tripod to video the person centred planning circle meeting. I also used the room as it was set up by the group, locating the camera in one corner, where I could have a clean sweep of all the members. Henley cited in (Prosser 1998), views the position of the participants and the camera lens as particularly important. It requires decisions to be made also regarding how long to film, how to frame the shots, and when to stop filming. These contingencies were resolved at the time of production by asking the participants. They were also reassured that filming would cease if anyone left the room, or indicated I should stop. The film produced, represents a general ethnographic account that was used in conjunction with other data collected, to enrich the research study. The positions of the participants can be seen in **figure 3**.

Figure 3. Participant and camera positions for circle meeting.



VIDEO ELICITATION CLIPS

Three clips were chosen for the video elicitation interviews, the total length of time for the three clips was twenty minutes. These clips were taken from the video of the whole circle meeting, which lasted two and a half hours. It was decided not to involve the other group members in the choice of the video clips. I considered this could prejudice the video-elicitation process if they had prior knowledge of the content of the video, each of them would be shown. This is a view endorsed by (Le Compte and Preissle Goetz 1982) who warn against utilising “a priori” constructs, or relationships within ethnographic research. Although what was of interest was the group participants’ responses to the events shown in the video clips (Henry and Fetters 2012). Of particular interest was what they recalled from the meeting, after viewing the video elicitation clips. Did this generate new reflections on how the group should support Keith in the future? Did it result in any reflections on past actions? What “essence”, “truth”, or underlying phenomena (Jewitt 2012) was described or present? This was of significance as it related to the suggestion that this may constitute the “essence”, or “truth”, of how the group supported Keith. Most of the group members chose to be interviewed in pairs, and I will reflect on this in the later data analysis. The clips were chosen because they contained a variety of participant interactions.

The first clip was ten minutes long and was chosen because it shows Keith controlling the meeting, and asking for help from the group in solving a particular problem. The second clip was chosen because it showed the circle members reassuring Keith regarding a particular issue, and also encouraging him to make the decision himself, with their help. It was six minutes in length. The final clip was four minutes long and shows Keith trying to encourage Susan to participate, and also

concludes with a discussion of what Keith has achieved since having circle meetings.

VIDEO ELICITATION INTERVIEWS

A total of five interviews were conducted, three of these were with pairs of participants who were partners: Keith and Susan, Nigel and Charlotte and Tom and Sharon. Dawn and Janet requested individual interviews. Since this study has focussed on an inclusive approach, it was important that the circle members chose their own interview locations and partners. It was also important for them to be relaxed. Anxious interviewees were unlikely to produce effective interview data. This is a view supported by (Rymes 2003) who interviewed children at home and in classrooms. She found that they were less responsive in the formal classroom situations. Home situations or talking in the car yielded the richest narrative content.

All video elicitation interviews in this study were audio recorded with permission, and these were later transcribed. Individuals were encouraged to choose their own time and venues. In fact, most of the individuals chose to be interviewed at home. Dawn and Janet were interviewed at work in a suitable meeting room. The remaining interviews all took place at peoples homes. The interview technique was informal, unstructured, open- ended and in- depth, and rather similar to having a conversation. A set of self- instructions was produced for the researcher to be used as guidance (rather than a set of prescribed standardised questions), and these were used to initiate all of the interviews as recommended by (Loftland and Loftland 1984). This provided uniformity across all the interviews, and enhanced the validity of the subsequent data gathered. They are included in **Appendix 7**. Prompts were

occasionally used to obtain clarification or generate additional responses. This process of responding directly to the participants through open-ended informal conversational interviews, removes any anxieties or misconceptions the participants may have. Since the researcher is responding directly to these as it occurs. It also reinforces the participant's status as active participants, not subjects. They are producing their own conversational contributions to the research, which are valued by the researcher, and will result in generating new knowledge regarding the topics covered in both the interview, and subsequently theorising around the research question (Moustakas 1994). They are also involved in a process that is concerned with the theory of possibility, as opposed to a theory of predictability. This ensures that participants and researcher are generating new knowledge, and linking theory to practice in an innovative and unique way to that particular group, in this case Keith's circle of support (McIntyre 2008).

None of the interviews exceeded two hours in length. Susan and Keith's interviews took place over two sessions both lasting one and a half hours in length. This was because Susan and Keith required a great deal of clarification and explanation during the interview, and additional prompting. I had to keep asking Keith to explain certain items that arose during the interview. He assumed prior knowledge and understanding regarding words and phrases he used and events that occurred. An example is included in the extract below from Keith's and Susan's interview, (copies of transcriptions are included in **Appendix 7**).

**K13. Keith. “ I don't really know, I guess it's trying to problem solve.
Chris. and what does that mean?**

Keith. It means you've got a big problem, and you are trying to diffuse the main problem. You are trying to get rid of the nuisance, or look at or give a different approach in other words.

Chris. and did it sort the problem out for you?

Keith. It did actually because when I went to the meeting he was very apologetic and asked me what was bugging me, and I said they were, there was a certain member that I didn't get on with at all, and that's when it all stopped. I don't want to go into too much detail.

Chris. But you sorted it out and were happy with what happened?

Keith Yes".

A similar issue was encountered by (Tuffrey-Wijne, Bernal et al. 2008) leading them to conclude that sometimes people with learning disabilities have very real problems understanding the nature of qualitative research. However, this should not prevent their inclusion, in fact quite the opposite (Burke 2003; Gilbert 2004; The Learning Difficulties Research Team 2006).

In total five audio interviews were completed. They were transcribed using Dragon Naturally Speaking (recorder edition 11.00) software. The audio files from the digital recorder had to be converted into a readable format for the software. This was quite challenging in itself, but usage of the Dragon software also had its problems since it failed to recognise all the participants' voices. Also it often confused words and meanings. The problem was resolved by dictating the content of the recorded interviews in the researcher's own voice.

The individual transcriptions were produced using the techniques required for qualitative analysis (Saldana 2009). This suggests using an audio recording of the interview. Since this type of analysis is concerned with an interpretation of the meaning of the participants' account overall. It was unnecessary to produce a detailed, line numbered transcription. However, verbatim transcriptions of the interviews were carried out. Later during thematic analysis, each distinct section, where the content reflected specific themes, was numbered. In this case the themes represented a cluster of repeating ideas, or statements obtained from the interviews. These ideas were later clustered together and conceptualised by the researcher. The researcher also noted on the transcription any additional interactions thought significant, for example when individuals laughed, who they were looking at when talking, and when interruptions occurred. Also noted were occasions when names were omitted from the transcript, in order to preserve confidentiality.

Also transcribed was the video of the whole circle of support meeting this was because I wanted to utilise in the analysis any non verbal interactions that may have occurred. I also recognised that the participants may not recall all the detail of the meeting during the video elicitation interviews.

ETHICAL CONSIDERATIONS

Any discussion of ethics must at first recognise that it is a very complex subject open to a great deal of differing speculation and interpretation. It does include recognising general principles, and increasingly rules. This is particularly relevant regarding the procedures and information required for applications to ethical committees. Indeed some authors, (Loftland and Loftland 1984) and (Mayan 2009)

view the process of ethics in academia as a process of systematising the academic workforce so that its outcomes are predictable, measurable and controllable. It is administered by what (Thrift 2004) terms “ dealers in virtue”. These are audit professionals whose sole purpose is to audit academic ethics. I hold the view that ethical decision making is a matter of judgement, using reason to arrive at an outcome which is morally acceptable, for the individual concerned, at that particular time. A decision is made in the person’s best interests using the least restrictive methods available, and causing no harm (Robson 2007) . The researcher needs to be sympathetic and intuitive; recognising that each time, the feelings and actions taken will be different depending on circumstances. Of course the definition of personhood is closely linked with this. Only defined persons are deemed to have rights, non persons as we have seen in previous chapters are not accorded the same rights or treated in an ethical manner. They are abused, injured, tortured, incarcerated and placed out of sight of society (Warnock 1998). In the field of learning disability there are plenty of cases where people have been treated in this way but fortunately legislation has sought to redress the balance (Warnock 2003).

The United Kingdom signed the United Nation Declaration of Human Rights as long ago as 1948, this contained many basic rights for all individuals. These included the right to be free and equal. These rights and freedoms apply to all without discrimination. Everyone has the right to life, to their own property and freedom of thought, opinions and expression of these. Citizens of the UK have certain fundamental human rights which government and public authorities are legally obliged to respect. These became law as part of the Human Rights Act 1998. The Human Rights Act 1998 gives legal effect in the UK to the fundamental rights

and freedoms contained in the European Convention on Human Rights (ECHR). These rights not only affect matters of life and death like freedom from torture and killing. They also affect an individual's rights in everyday life for example, what a person can say and do, their beliefs, their right to a fair trial, and many other similar basic entitlements. The rights are not absolute in that the government have the power to limit or control rights, but only in times of severe need or emergency. There are also individual duties, for example people have the responsibility to respect the rights of other people, and not exercise their individual rights in a way which is likely to stop others from being able to exercise theirs. It is important for every researcher to safeguard the rights of the individual participants. I was particularly aware of the need to avoid any form of coercion. This was particularly challenging, as I was already known to Keith and his group. It was difficult providing Keith with the reassurance he required to participate in the research, without overtly influencing his decision. This ethical dilemma was resolved following telephone conversations. However, the following extract from Keith and Susan's interview transcription, illustrates why Keith required additional support via telephone conversations.

K17. Chris.” I know you were not very keen to have the meeting, and you phoned me a few times didn't you. Can you say what that worry was about?

.Keith. Well I guess it was because I thought other students would be listening to my thoughts who I didn't even know or whatever, and they probably are.....

Chris. No one at the University will hear this except my supervisors, and I would only let them hear stuff I think I am having problems with ok. I want to reassure you.

Keith ok.

Chris. And when I write it up, if I think it's really sensitive stuff, and likely to upset people I won't put in people's names or services. Does that reassure you?

Keith. Yes it's fine".

The process of safeguarding rights and providing adequate support is often underestimated by those researching with people with learning disabilities. It requires a person centred approach and an ability to empathise with the individuals concerned. Time needs to be factored into any study to allow for these important eventualities (The Learning Difficulties Research Team 2006). However, the emphasis must be on treating people at all times with care and respect.

In addition to basic rights, and of particular relevance to people with learning disabilities and this study, is the Mental Capacity Act 2005. This act presumes people have capacity and that every adult has the right to make his or her own decisions and must be assumed to have capacity to do so, unless it is proved otherwise. Inherent within this is the right for individuals to be supported to make their own decisions. To enable this people must be given all appropriate assistance and support, before anyone concludes that they cannot make their own decisions. This would mean alternative means of communication would have to be employed before assessing a person's capacity. Individuals also must retain the right to make

what might be seen as eccentric or unwise decisions. However, anything done for, or on behalf of people without capacity must be in their best interests. This must be achieved in the least restrictive way with regard to their basic rights and freedoms. The Act sets out a single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time. It is a “decision-specific” test. No one can be labelled “incapable” as a result of a particular medical condition or diagnosis. Section 2 of the Act makes it clear that a lack of capacity cannot be established merely by reference to a person’s age, appearance, or any condition or aspect of a person’s behaviour which might lead others to make unjustified assumptions about capacity. Everything that is done for or on behalf of a person who lacks capacity must be in that person’s best interests. The Act provides a checklist of factors that decision-makers must work through in deciding what is in a person’s best interests. A person can put his/her wishes and feelings into a written statement if they so wish, which the person making the decision must consider. Also, carers and family members gain a right to be consulted. Although in this particular study no one actually lacked capacity it was required by the National Health Service Ethics committee that I had an awareness of the Act, and had made provision within the study.

I had informed the committee when I attended the committee meeting that the circle of support would make any decision regarding acting in the person’s best interests. If the person was mentally unwell a referral would be made to the appropriate local team for additional advice, support and if required treatment. This follows the advice and guidance in the NHS policies with regard to seeking consent to treatment, and supported decision- making when working with people with learning disabilities (Department of Health 2001; Department of Health 2007) .

The Mental Capacity Act also has clear guidelines relating to research involving or in relation to, a person lacking capacity. This must be lawfully carried out if an “appropriate body” (normally a Research Ethics Committee) agrees that the research is safe, relates to the person’s condition and cannot be done as effectively using people who have mental capacity. The research must produce a benefit to the person that outweighs any risk or burden. Alternatively, if it is to derive new scientific knowledge it must be of minimal risk to the person and be carried out with minimal intrusion or interference with their rights. Carers or nominated third parties must be consulted and agree that the person would want to join an approved research project. If the person shows any signs of resistance or indicates in any way that he or she does not wish to take part, the person must be withdrawn from the project immediately. These principles were clearly indicated to all participants and reinforced at the circle meeting. They were also included in the information sheet which is included as **Appendix 2**.

The main principle of any ethical approach is to do no wrong, or to do the greatest good (Todd 2005). It is not in anyone’s interests to cause harm, or otherwise adversely affect a research participant. However, safety for the researcher should also be considered. For example, is there risk or threat or abuse, psychological trauma as a result of what is disclosed during the research, or the risk of being placed in a compromising situation (Craig, Corden et al. 2000).

Since the area of study involved individual interviews with people, approval from a Research Ethics Board was required (Robson 2007). In addition individual guidelines with participants were agreed on the understanding that they could

withdraw at any time. Also, any written material was to be produced in a communication that was the preferred method for the individual concerned. This involved the production of a variety of easy to read and understand materials including an information sheet, consent forms and guidelines for meetings (Aitchison and Perez 2001). These are included as **Appendices 2 ,3 and 4**.

Throughout the study confidentiality and anonymity at all times was maintained. This was particularly important during the data collection phase of the study when individual transcriptions were produced, and also when transcribing the video of the circle meeting. The researcher ensured any potential confidentiality breaches were minimised by removing any named references, to either individuals or services. Also ensuring that any personal comments were only included if the individuals concerned gave permission. It was agreed with Keith that any references to personal care, health, sexuality, relationships, or comments that could be viewed as hurtful towards another person would also not be shared. An interesting dilemma arose when Keith asked to view all the other circle members' transcripts. I had to explain that although the research involved his meeting, and he was a research participant, so were the other circle members. It would therefore breach their individual confidentiality, unless they gave permission. The circle agreed that Keith would choose pseudo- names for the individual members, since the National Health Service ethics committee had insisted that no patient identifiable information could be included in the study. The whole issue of maintaining confidentiality and anonymity is a very difficult one for people generally and in particular people with learning disabilities. It is understandable that people would wish their own names to be used or to see what others think since it tells their story. The issue is that in

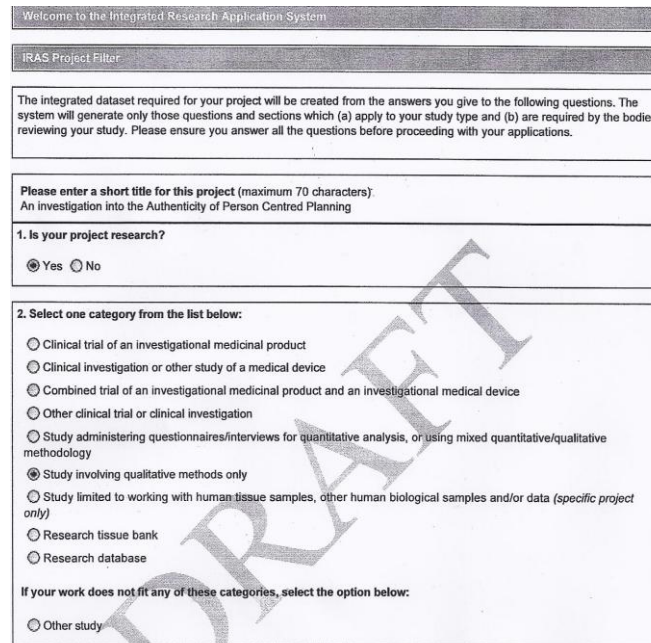
maintaining anonymity and confidentiality all the participants, their relatives, and people who support them in their daily life, become protected from unwelcome publicity, and press intrusion (Tuffrey-Wijne, Bernal et al. 2008). The circle agreed that Keith would be involved in choosing how the research was presented, should the opportunity arise to present at future events. This approach is advocated by many authors including (Pryke, Rose et al. 2004; Pink 2005; McIntyre 2008).

I hope this illustrates some of the ethical dilemmas and challenges that arose in this study. Also how people with learning disabilities can be supported to become co-researchers promoting inclusion, equality and citizen advocacy (The Learning Difficulties Research Team 2006). These factors were a particular concern of the various ethics committees who also wanted to ensure that the research was safe, rigorous and valid.

ETHICS COMMITTEES

An application was made to the University of Exeter Graduate School of Education Ethics Committee, and also to the National Health Service Local Research Ethics Committee. The approval forms are included in **Appendix 6**. The former took less than a month to pass the study, the latter over eighteen months. The NHS Ethics Committee has an online form that has to be completed, and once approved by the Ethics Committee a site specific form must be completed, and passed by the ethics committee responsible for the geographical area where study will take place. My experience of using the online form was that it was very difficult to use, very complicated and highly biased towards medical/quantitative research

methods. For example, in the following extract (included as **Figure 4**) Question 2 of the form required selection from a number of categories only one was qualitative:



Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project (maximum 70 characters):
An investigation into the Authenticity of Person Centred Planning

1. Is your project research?
 Yes No

2. Select one category from the list below:

- Clinical trial of an investigational medicinal product
- Clinical investigation or other study of a medical device
- Combined trial of an investigational medicinal product and an investigational medical device
- Other clinical trial or clinical investigation
- Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
- Study involving qualitative methods only
- Study limited to working with human tissue samples, other human biological samples and/or data (specific project only)
- Research tissue bank
- Research database

If your work does not fit any of these categories, select the option below:

- Other study

Figure 4.

National Health Service Integrated Research Application System (I.R.A.S.),Form, Version 3.0 (June 2010),pg 1.

There was no support to complete the form available early on in the application process. Eventually support became available towards the end of the application process. The researcher attended the Ethics Committee in person to present the study. The majority of the members were doctors or nurses, with little or no knowledge of qualitative methods, judging by the questions asked. Areas of particular concern were the use of photographs identifying individuals (even if they gave consent). What would happen to the visual data after the study? and finally the

requirement for the production of a variety of easy- to- read and understand materials. For example, inclusion on the information sheet with regard to the support available if one of the individuals became distressed, and an assurance that individuals could withdraw from the study at any time.

After four application attempts, all was finally passed. Then there was a site specific application which required further information, including what legal liability was available, and what risk assessments were in place. I think this all clearly illustrates what a bureaucratic organisation the National Health Service is, and how it is dominated by medicalised models of research. It is also very risk adverse, and very aware of the potentiality for litigation. When one considers that most of the NHS research is based on clinical trials it can easily be seen how the research application process is affected. Thrift (2004) describes how increasingly in the USA Ethics Committee's in universities, hospitals and private research organisations have imposed a rule based biomedical ethics approach, founded on the "Protecting Human Subjects Handbook". This makes it very difficult for many qualitative studies to be passed, particularly those undertaken in the field, rather than in the confines of the laboratory or other closely controlled situations.

DATA ANALYSIS

The initial analysis across all data was intuitive and thematic, and looked for patterns and themes arising from within the data. The methodology for this study was positioned within a phenomenological foundation. This meant examining data for content, discourses, patterns and relationships. These would hopefully identify the subjective human experience of the members of Keith's circle of support.

Moustakas (1994) considers one of the advantages of this type of analysis is that it promotes a deeper and richer understanding. It extrapolates data beyond what is actually represented, whether that be visual, text or audio. This is particularly important in a phenomenological study since researchers are concerned with what constitutes the “truth” or “essence” in human interactions and relationships.

Boyatzis (1998) considers that a theme can be observed, and/or interpreted directly from information in the data (manifest level), or it can be obtained from underlying phenomenon (latent level). Both of these methods were employed in this study since the latter is a critical factor within interpretive phenomenological analysis.

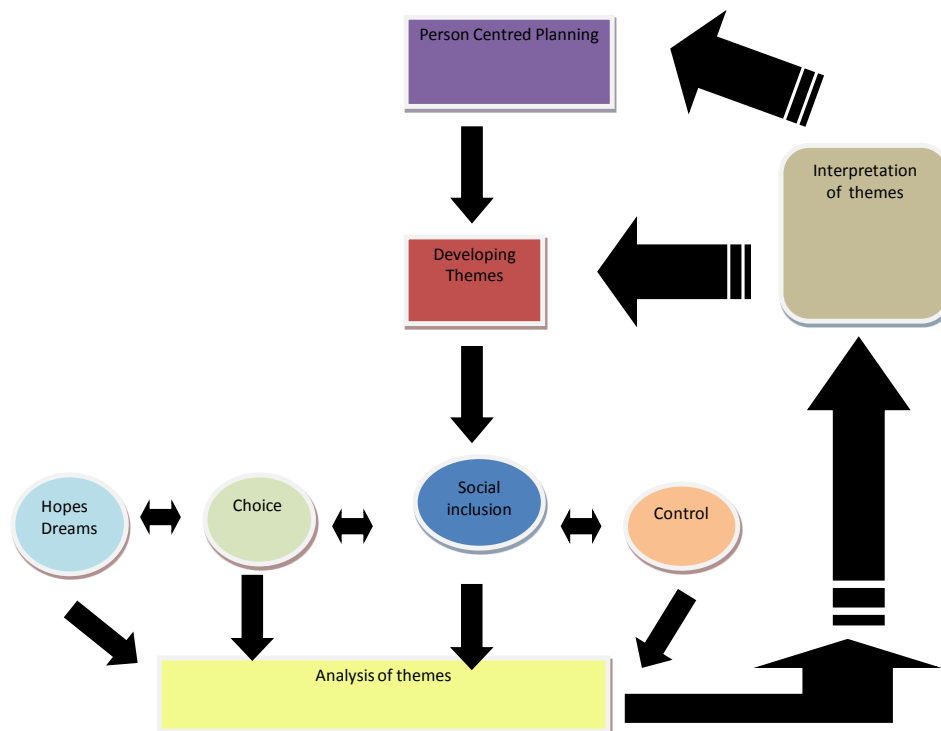
The definition of theme varies from author to author but generally a theme represents a phrase or sentence that illustrates what a unit of data means (Saldana 2009). A theme can be considered as a way of labelling a set of data to produce a topic that organises a group of repeating ideas (Auerbach and Silverstein 2003). Similar themes are then clustered together producing higher level theoretical constructs. These are then, “winnowed down”, some are re-named subsumed, promoted or relegated until the main overarching themes are produced. Alternatively an integrative theme is produced, bringing various themes together into a coherent conceptual topic derived from the data as a corpus (Rubin and Rubin 1995) . This describes the methods employed in this study.

These methods were applied to the visual data represented in Keith’s seven person centred planning graphics (see **Appendix 5**). However, the content of the plans dictated how the data was interpreted. For example the circle of friends (described in the table on page 137) was grouped into family, professionals, friends,

community members and others. This also ensured that no names were used. I was sensitive to the fact that some members are closer to Keith than others, and it was important to keep this information anonymous. Keith was also particularly concerned that no individual was upset from his circle, and he was aware of these sensitive issues.

It had originally been suggested in the study rationale submitted to the Ethics Committees that five themes were of importance to this study. **Figure 5** illustrates these themes and the analysis anticipated at this early stage. However, I would also like to emphasise that the data collected generated many new themes and interpretations. It also proved far more complex than that illustrated (see **Appendix 9**).

Figure 5. Flow Chart for Person Centred Planning Research Study.



N.B. Arrows indicate the relationships and links between themes and the anticipated interpretative process.

The five pre-existing themes (PCP, choice, control, social inclusion, hope/dreams) were combined with those from Keith's person centred planning graphics. This became the initial stage of the data analysis.

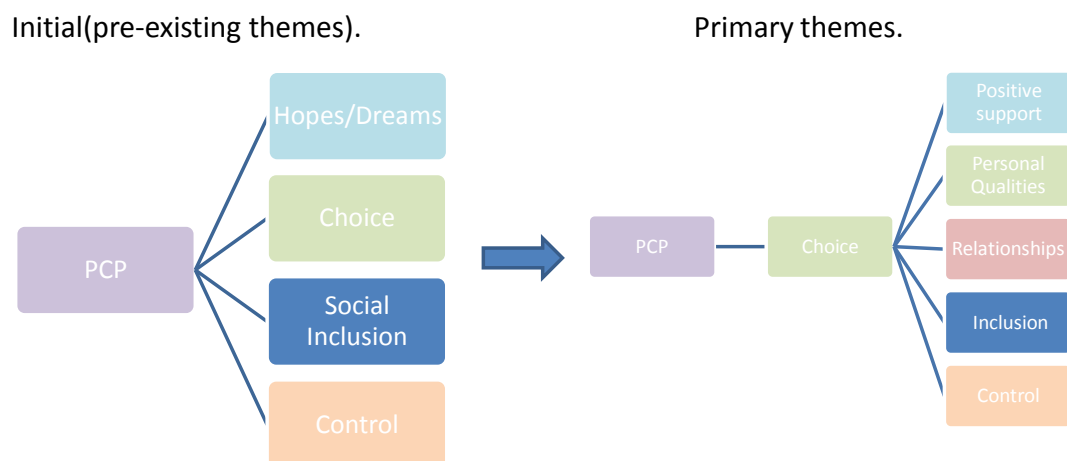
The second stage of the analysis involved listening to the audio recordings of the five video elicitation interviews. This built on the initial themes and enabled a re-examination of the transcriptions. Copies of transcriptions are included in **Appendix 7**. Each transcript was examined and divided into numbered sections. These related to chunks of text with a particular meaning, pattern, or phenomenological resonance of content. The thematic content of each section was noted and also any phenomenological meanings. This process was repeated with the transcript of the circle meeting video (see **Appendix 7**). These were compared across data types (pre existing themes, person centred planning graphics and video transcripts of elicitation interviews and the circle), and new themes emerged, some existing themes were promoted and merged, some demoted, until a cohesive framework of emerging themes was produced. **Table 2** on page 128 illustrates this process.

Table 2. Extract from circle meeting transcript illustrating the thematic development.

Transcription	Developing themes	Exploratory comments
<p>T5.Janet:You're the first person that needs to vote don't you.</p> <p>Dawn: It's up to you Keith. Keith: Do I really want to put myself through all this disappointment again. Dawn: This is just a suggestion shall I speak with (name omitted), I know we have done this before but I'm happy if we go and have a conversation with him, but you need to be really honest and tell him exactly how you are feeling.</p> <p>Keith: I feel used to be honest.</p> <p>Charlotte: You need to get a contract with him. Keith: Trouble is I don't like to go in all bolshie. Dawn: It's not about being bolshie, it's about being honest and I think they need a dose of honesty. I think you are within your rights to say you are disappointed.</p> <p>Charlotte: You'd do ok if Deb was with you. Keith: Yeah. Dawn: and you'd say it to me wouldn't you. I will be there to support you, but you will have to say how you feel. Keith: The only thing is I will let people down, and that's the last thing I want to do.</p> <p>Charlotte: They've let you down.</p> <p>Nigel They've let you down badly.</p>	<p>Advice.</p> <p>Guidance.</p> <p>Problem solving.</p> <p>Power/Control.</p> <p>Resource knowledge.</p> <p>Personal qualities.</p> <p>Promoting advocacy.</p> <p>Rights/advocacy.</p> <p>Positive support.</p> <p>Advocacy. Power.</p> <p>Control.</p> <p>Affirmation.</p>	<p>This illustrates the process of guided decision making this group employs.</p> <p>By a process of positive affirmation Keith is encouraged to take control of this problem.</p> <p>He is offered positive support but is given the choice and control over the situation and the final decision. The group utilise their own knowledge to offer Keith a resolution to the problem. Keith is given power, control and advocacy is encouraged.</p>

This process follows the interactive and inductive analysis as described by (Smith 2007). This recognises the development of a dialogue between the data and researcher as particularly important. It draws out relationships, patterns and nuances from within the data. Comparing these with multiple data types, in this study yielded a greater complexity of thematic categories than initially anticipated. Also it assisted in contextualising both the individual, and group meanings around the emerging themes. This process can be illustrated in **Figure 6**. It represents the process of analysis and interpretation of the initial themes (which included the pre-existing themes of PCP, hopes and dreams, social inclusion, choice and control), and the development of primary.

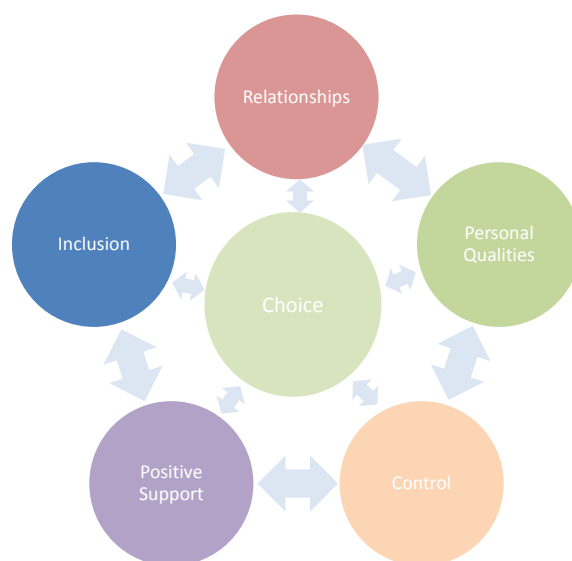
Figure 6. Thematic Development



This represented a first take on the study of the world of Keith's circle. It represented the circle as it was immediately experienced by those participating, and captured within the data. It was also developmental and intuitive and resulted in Choice being promoted as a major theme, and PCP being removed from the final conceptual model.

The final stage was the secondary thematic analysis. This provided a deeper understanding of the nature of the experience of participating in Keith's circle. By a process of conceptualisation with the material in the literature review, my own experience as a learning disability nurse, and an intimate connection with the data generated in this study (produced by constantly reviewing and analysing all the data used in this study) new phenomenological descriptions and relationships were produced. These were consolidated with the primary themes to produce a conceptual model, shown in **Figure 7**. The thematic development is discussed in greater detail in the next chapter of this thesis. A detailed version of the conceptual model of attributes can be viewed in **Appendix 8**

Figure 7. The developing conceptual model of attributes.



The process of thematic development has been described by (Van Maanen 1990) who views themes as insightful discoveries. They are the way of capturing the phenomenon the researcher is trying to understand; in this case person centred planning. It also represents researchers' efforts to uncover the underlying meaning of the data. To make sense of what is seen, and ultimately to lead to a discovery of the relationships between interconnected themes This leads to the phenomenological description, and in this study, the development of a conceptual model. This represents the gestalt of the whole process combining thematic development with ethnographic/ discourse analysis.

A particular problem associated with new researchers is thematic development, and especially so with an ethnographic/inclusive study because the researcher is so immersed in the culture (Mayan 2009). However, this was not the case in this study. The primary thematic development provided a focus for secondary thematic analysis via the initial thematic labels and categories. It also provided the initiation of thinking in a conceptual and theoretical level. This resulted in the refining, and re-organisation of themes into broader thematic categories. Some ideas were dropped and reconceptualised, some themes merged or subsumed. For example, the theme of gifts became a sub- theme in personal qualities mainly because individuals had problems understanding the meaning of the term(although this is discussed in detail in the following chapter), personal qualities offered a clearer description (Saldana 2009). The sequence of research is outlined as a table in **Table 3**. This gives an indication of the sequence of data collection. It was helpful to attempt to conduct all the interviews around the same time. However, personal circumstance dictated when they could be conducted, for example some people had

holidays, illness and work commitments. I travelled to the individuals preferred locations to also minimise any inconvenience.

Table 3. Research Activity Sequence.

Date	Research Activity	Location
19.1.2011.	Invitation to participate letter sent to Keith	
6.4.2011.	Video Keith's circle meeting	Keith's parental home
30.5.2011.	Dawn's video elicitation interview	Dawns workplace
8.6.2011.	Janet's video elicitation interview	Janet's workplace
10.6.2011.	Tom & Sharon's elicitation interview	Tom and Sharon's home
16.6.2011.	Keith and Susan's elicitation interview	Keith's flat
17.6.2011.	Keith and Susan's elicitation interview	Keith's flat
20.5.2011.	Dawn and Nigel's elicitation interview	Dawn and Keith's home

The following chapter describes and interprets the findings of this study in greater detail. It also includes a discussion of the findings, and how they are related to the theoretical positions described in the literature review. How this study contributes to the topic of person centred planning is also discussed.

CHAPTER 3 FINDINGS AND DISCUSSION

INTRODUCTION

This chapter of this thesis concerns itself with presenting the findings and discussing them with relevance to the research questions posed, and the theoretical stances adopted. Although an inductive process is utilised, the emphasis is on findings guiding the research, not the other way round (Mayan 2009). This ensures the work is comprehensive but has rigour, arising out of theorising about the data, and the possibilities it has generated (Potter 2002).

The discussion section describes the conceptual model and its individual components. These are related to Keith's circle of support, and person centred planning generally. It also includes a section on ethics and authenticity, analysing these within the existential and social philosophical contexts described in this study.

FINDINGS

This section of this study discusses the thematic analysis and the themes gathered and analysed from all the data used, but begins with a discussion of Keith's person centred planning graphics.

PERSON CENTRED PLANNING GRAPHIC/ DOCUMENTARY DATA

Seven of Keith's person centred planning graphics were used (**Appendix 5**). These included his relationship map, two sections of his P.A.T.H. his dreams, his interests and personal qualities, what people like and admire about him, and his gifts and worries (from his perspective).

The only manipulation that took place was the cropping of, and deletion of some names. Also the removal of personal information, that Keith did not wish to share with others. Manipulation of visual data has been described as acceptable by some authors since it contributes to the development of a visual anthology, and is thus an important part of any visual ethnographic record (Pink 2005). Others view it as manipulation of data leading to lack of research rigour (Prosser 1998). I took the view that these were copies of original images related to Keith's life, and the only manipulation should respect his wishes to preserve confidentiality.

Copies of all the graphics which form the bulk of Keith's person centred plan can be seen in **Appendix 5**, with the exception of his relationship map. This has not been included because it has individual names, and illustrates how close people were to Keith. Keith was very aware that people could not only be identified, but that they may be upset if certain individuals were seen as closer to him than others.

Each graphic was analysed and themes developed (**Table 4**). Descriptions of the content of each plan were noted and used to inform the thematic development. It was important to note the content of each plan since this illustrates how plans can be used to develop an individual's life. The descriptions were utilised to develop the thematic analysis across all the types of data, and in addition inform the theoretical/conceptual thinking critical to the process of writing up. Although in this study there is considerable overlap during the stages of thematic analysis and writing up the theoretical content. This is a view supported by (Smith, Flowers et al. 2012). Some themes became prominent others less so. This is reflected as the writing proceeds. The descriptive content provides additional support to this process

enriching the final analysis, and developing phenomenological interpretation and theorisation. This is described in greater detail in the discussion section of this chapter.

Table 4. Thematic development from Keith’s Person Centred Planning graphics

Data Label	Descriptor	Data Theme
Interests and gifts	Quizzes, sports, debates, VW beetles, autobiography, music, mugs, entertainment, news, radio, British comedy ,modern history.	Personal interests. Gifts.
	Family.	Relationships.
	Listener, cheers others up, good communicator, loyal, public speaking.	Personal qualities. Advocacy.
Keith’s worries	Death, bullying, people being bossy, not liking himself, missing his sister, missing friends,	Individual concerns.
	can’t meet people, can’t get to money.	Resource deficits.
Keith’s gifts	Dancing, singing, speaking up in meetings, confidence, getting on with people, lovely smile, planning, talking.	Hopes/dreams. Gifts, advocacy, self advocacy, personal qualities, PCP,
P.A.T.H. Where Keith is now.	Has a circle of friends unpaid work, a large number of hobbies and interests and goes for regular holidays. The only area where he is	Community knowledge. Community presence.

	looking for opportunities is in developing a social life.	Equality. Choices, Social relationships/ activities.
P.A.T.H. The future.	move to supported living, to see more friends, leave one of his jobs, to travel abroad, have more meals out, go singing, pub quiz nights.	Choice, control. Community presence. Friendships. Hopes/dreams. Social relationships /activities/Interests.

The thematic analysis resulted in the five initial predetermined themes outlined in the methodology section being expanded to sixteen. They now include: Relationships, Personal qualities, Friendships, Community presence, Equality, Advocacy, Community knowledge, Resources (including deficits), Individual concerns, Hopes/dreams, Gifts and Personal interests (see **Appendix 9**).

It is often very useful to have a predetermined list of themes prior to field testing. It provides a set of core themes derived from the literature reviews, reflects the theoretical principles and foundations of this study, and the research stance taken. It also represents the researcher's own knowledge and experience in the field of learning disability (Miles and Huberman 1994). This is particularly relevant since the researcher is an active participant in Keith's, and other individual's circle of support. The initial themes are later expanded into primary emergent themes with the analysis of elicitation interviews and video of the circle meeting.

RELATIONSHIP MAP

Keith's relationship map (doughnut) has been represented as a table. It used the same format as that illustrated in **Figure 2** on pg 72. The individuals were categorised, taking into consideration which circle of the map they appeared in. Also Keith confirmed the individuals' positions, and the categories used. The categories were: friends (some in his circle of intimacy, most in his circle of friendship), family (extended family outside his circle of intimacy, some in his circle of friendship), close family (those within his circle of intimacy), professionals paid (those on the circle of participation), professionals un-paid (most in his circle of friendship and all in his circle of support), people with a personal budget (people he works with, mostly within the circle of participation) and others (on the periphery or outside of the circle of participation). These can be seen in **Table 5** below:

Table 5. Keith's Relationship Map

Family	Friends	Close family	Professionals Paid	Professionals Un-paid	People with a personal budget	Others
16	9	3	8	6	5	10

It can be seen that most of Keith's relationships are with others and family. Many of those included as others either have a learning disability or have connections with learning disability services for example members of staff of services he once used. A small number of people in Keith's life also have personal budgets. He has a small number of friends and close family, and a significant number of

professionals paid and unpaid involved in his life. The others included a number of people who provide other paid services for example taxi drivers.

INTERVIEW DATA

As a result of the initial listening to the five audio data files collected from the video elicitation interviews, nineteen primary emergent themes resulted. This represented a “first take” on hearing the data, an initial attempt at familiarising oneself with the data before more in- depth transcriptional analysis (Smith, Flowers et al. 2012). It included the following themes:

PCP, Choice, Control, Community, Dreams, Personal growth, Personal reflection, Policies, Relationships, Power, Affirmation, Positive support, Friendships, Family, Professionals, Development, Social skills, Labelling, Behaviour.

PRIMARY THEMES

A further analysis was carried out using coding for thematic categories on a transcription of the audio data for each of the five interviewees. Each identified theme was given a label, and a descriptor which related to a numbered section in the audio transcript for example, J6 in Janet’s transcript refers to control:

J6 "I suppose it's who Keith wants there, that's the main thing I can't say more than that".

Any emerging themes were coded in this manner, and also significant comments noted to be used in later analysis. Particularly noted were any comments related to attempting to understand how the individuals experienced the circle of support. This related to my interest in attempting to identify the

existential/phenomenological experience. It also related to a better understanding of the “essence” or “truth” of the experience for group members, as discussed in the literature review.

VIDEO OF CIRCLE MEETING

A transcription was produced of the whole circle meeting using an identical coding method to analyse the data. Themes were coded and descriptive comments noted. These were combined with the other primary data analysis. As a result of this coding fifty two themes evolved. A full list of these can be viewed in **Appendix 9**.

SECONDARY THEMES

One of the decisions taken at this stage of the analysis was to closely examine the thematic categories. Some were merged, combined or renamed as the result of the process of contextualising, referring to the transcriptions, and constantly reviewing all the data. There was a constant process of refinement. This included searching for commonality, convergence, divergence, and originality. Recurrent themes were defined not in terms of how many times they occurred, but in terms of their significant contribution to the content of the data as a corpus. For example, in reviewing the transcripts of the interviews and the circle meeting, person centred planning and choice were consistently reflected. This eventually resulted in the decision to include these elements as central conceptual themes, since they had significance to all the data. It was later decided to remove PCP as a central theme, since PCP represented the context for the whole study.

Further themes were combined or merged until the five main thematic categories of Positive support, Relationships, Inclusion, Control and Personal

Qualities resulted. These were linked with 19 sub themes. For example, problem solving became a sub- theme to positive support. Problem solving appeared in the data as one of the methods utilised by this group. It is used in a manner that supports the process of positive support for Keith. Indeed the group utilise positive support constantly in their interactions, hence it became a main theme. It was also very closely linked with affirmation, advice and guidance.

The thematic stages and the number of themes developed is summarised in the table included in **Table 6**. This is an extract from the table included in **Appendix 9**. That illustrates thematic development in greater detail, including the secondary thematic development. This eventually produced the final conceptual model. A detailed version of this can be seen in **Appendix 8**.

Table 6. Thematic developments across all data types in the study.

Initial Themes		Primary Themes		Secondary Themes		
Pre Existent	Visual (PCP'S)	Interviews	Interviews & Video	Conceptual	Main Theme	Sub Theme
5	16	19	52	2	5	19

DISCUSSION

This section follows broadly the themes developed from all the data(see **Appendix 9**), and it illustrates how they relate to the research/philosophical positions contained within the literature review (Smith, Flowers et al. 2012) .Each theme will

be discussed individually, with a particular reference to ethnographic/discourse analysis later in this Chapter. This will draw on all the data but particularly that which relates to Keith.

It is important that whilst many of the themes developed from the data are those that were directly observed or drawn as descriptors from analysis, some have a phenomenological basis. An important component is how people reflect on the lived experience, and allied with this is how the researcher and the person interprets this experience in the situational contexts in which they occur (Smith, Flowers et al. 2012). These latent metaphysical themes represent how humans experience the world in which they live, and importantly how they reflect upon it (Van Maanen 1990). It also provides insight into how the circle members view the “world of the circle”, and the world at large.

The development of the conceptual model will also be described, and how this can be used as an aid to guide authentic person centred planning.

PERSON CENTRED PLANNING PRINCIPLES.

At the centre of the circle group’s activities, are many of the principles and features of person centred planning. For this reason it was initially included at the centre of the conceptual model, since it was thought to represent a core conceptual theme highlighted from the data (see **Appendix 8**). It has been described by some authors as the heart and soul of the whole process (Mount 2002). For that reason it was eventually removed from the conceptual model since the process of person centred planning is implicit, and signifies what the whole model means and represents. However, the basic principles highlighted within the data, and discussed

in the literature review contribute to any review of how authentic person centred planning, hence their inclusion here.

Person centred planning puts the individual focussed person, central to the circle group, and all its activities. Clearly, in this circle Keith is the focus of everyone's attention. Not only that, but he also facilitates his own meetings (Ritchie, Sanderson et al. 2003). This is a core principle to any person centred plan. Without the person being the focus of all attention and planning, the meeting becomes just another review (Dufresne 2010). It is interesting to note that when Keith left the circle meeting (T10 in the video transcript **Appendix 7**), all planning conversation stopped and he initiated the meeting planning again by starting off with a joke:

T11.Keith: "Me and Susan had a laugh, we were having tea, and we got this woman about 25 or 26".

This is another key feature of the meeting; it should be enjoyable and fun for all the participants. Indeed many of the circle members report that they look forward to the meetings, and would like to have a circle meeting of their own to sort out life's problems. Often the group combine a meeting with another event, for example a birthday celebration:

T21.Keith. "That meeting was a kind of birthday party as well.

Chris. do you think that's important, the pair of you?

Keith. Yeah it's got to be casual anyway.

Susan. It's nice to have fun".

Keith is now a great supporter of person centred planning, but this wasn't always the case. As he states in the following extract he was uncertain at first:

K24. Keith. "Brilliant they give me good advice. I wouldn't be without them now.

Chris. yes, because to begin with you were not sure?

Keith. yes I was very wary.

Chris. Do you want to say why that was?

Keith. Well I was always brought up not to air my problems in public, and not bother people with my problems, and just muddle through on my own. It's nice that we call a meeting and we sort a lot of stuff out".

Clearly Keith's parents have had a profound influence on him (this will be discussed in greater detail in the relationships section), but possibly his experience of other learning disability services has also shaped his view. He describes being constantly let down, and disappointed by services. The most recent occasion was when he was excluded from the learning disability service on intelligence quotient alone. Please see the transcript section below from his parents:

S21. Tom. "No it's good for him, he knows it is there in the background, and he can call a meeting when he needs it. The main thing for the circle was when he was downgraded, that broke his heart when he came up to him and said that to him that night.

Chris. you mean the (name omitted)"?

S22. Sharon. “Yes when he came to the meeting and said he didn’t have a learning disability.

Tom. That’s when the circle came together and helped him with various ideas they came up with”.

The kind of treatment Keith’s parents describe is unfortunately commonplace in spite of policies stating the contrary (Department of Health 2001). One way of not being disappointed is not to get involved in the first place. To keep statutory services at a distance is a way of protecting yourself from constantly failing to achieve. If you feel powerless the process of contact with professional and services is more likely to be oppressive rather than liberating (Gomm 1998).

In the circle Keith not only feels secure amongst likeminded people, but he is liberated. This is evidenced in the way he controls and chairs the meeting, often interrupting or redirecting the conversation. He enjoys his meeting because the people present are all there to help him and will not “nag him to death”. He likes to get other people’s views on the issues that affect him, and then make up his own mind. This process of continually listening, reflecting on what is said and then making a decision is a very important part of person centred planning (Routledge, Sanderson et al. 2002). However, this group take it a stage further in that they offer through a process of guided reflection and problem solving, a resolution to an issue without telling Keith what he must do. Dawn describes this in some detail as affirmation:

D5. “I think for him it’s about affirmation and confidence, it’s about

having people behind him to do that because I think he still does it all himself even though he doesn't think he does, and I think sometimes you have to have a lot of conversations with him to make him realise it is his decision and it's the right decision and, there is guidance involved there and I'd be lying if I said there wasn't but its guidance to help him come to the right decision”.

It is interesting to note that family and friends are active participating members of the circle. Keith's circle of support illustrated that many of his contacts are with family or friends. This could be viewed as somewhat negative if one considers social integration, and promoting a social presence in the community, a key outcome for person centred planning. However, his family and friends are supporting him, to develop community links and relationships. Often this is how people with learning disabilities develop community connections. Initially, with the support of those they know well, and then later when links have been established, members of the community. This is a critical component of the theory of Normalisation as described by (Wolfensberger 1972). What appears to be important to Keith is having people who are fun, casual, and think in a similar way to himself. The meeting although he facilitates it, is different to a formal review meeting. Interestingly no minutes are ever taken, but the group follow up on all agreed actions:

S13. Sharon. “since the meeting things have worked because Dawn has done what she said, she has talked with him and the (name omitted), and got it all sorted. He now goes by himself with their transport and does the presentations. He has got his new uniform and he seems very

happy there now. I think he was forgotten higher up not with the people he trains with”.

There is also a non- human member of the circle, Buddy Keith’s dog. At first it may appear that his inclusion is not relevant, but for Keith he is an important part of his life. This further increases the ambiance of the meeting so that Keith is relaxed and at ease. This is an important factor often overlooked. So often meetings take place in service areas not chosen by the person and are time limited. In such situations the constraints imposed make it highly unlikely that any creative planning will take place (O’ Brien 2006).

It is also important that the circle members find the meetings enjoyable. There is also the issue of not have any anxieties about attending, coupled with the pleasure derived from seeing Keith develop as a person. In such situations individuals are more likely to make a commitment to the person. Dawn’s transcript below highlights these points:

D9. Chris. “So if I said to you that what kind of feelings does it bring up for you, that little clip.

Dawn. well for me I really enjoyed Keith's circle meetings and I think they're really productive. I look forward to that, and it's something I enjoy because I don't feel there can be any issues, or is it doesn't worry me to go. I think everybody is really open to what the group decide. I love the fact that Keith is the Chair. He interjects there in that clip because that is different from when we started, he sat there very quietly and used to let us all talk. You can see that he totally knows this is his

meeting and that we are there for him, and he has his say and I think that's really important and positive. I think it is a really good environment to have it at mum and dad's. I think it works for Keith. I think if we took it out of that environment it would make him anxious. I think his meetings worked really well".

This group certainly use all of the key principles required for person centred planning to be successful, as outlined in the literature review of this study. Keith is at the core of the meeting, and all decision- making is centred on him. The meetings are enjoyed by all the participants. They take place in an environment that is homely and inviting, not an office or service environment. The meetings are productive, and do not produce any anxieties or pressure for those that attend. A unique aspect of the manner in which this circle work together, is the process of guided decision- making. This is followed by affirmation, a process of assisting the decision- making by positive encouragement. This enables Keith to make the final decision on the issue discussed. Keith is also accorded full personhood, as are all the members. There appears to be a dynamic within the group, which fosters positive support and decision- making. There were no instances of conflict, and any disagreements are quickly and sympathetically resolved. Indeed the group positively encourage Keith (through their supportive behaviour), to interject and chair the meeting. Clearly relationships are a very important aspect of this group, and this will be the next theme to be discussed.

Relationships

Relationships are not only important with regard to person centred planning, but they

are an important factor in everyone's life. They influence how people develop as individuals. They include developing individual personality, interests, friends and community connections (see **Figure 8** which illustrates the thematic relationships developed in this study).

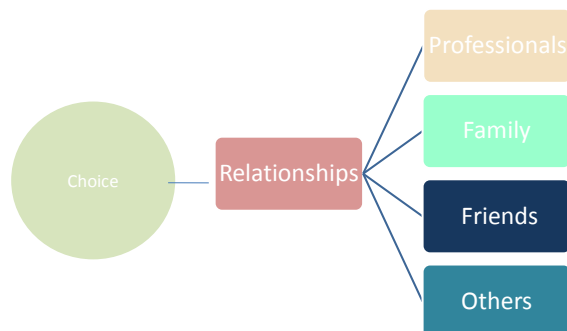


Figure 8. Relationships themes.

Relationships also shape the society and culture lived in, and the relationships the individual develops (Blumer 1980). Often in relationships there are significantly important individuals or groups. The setting and context in which the relationship has formed is also important, particularly the issues of power, control and emotional responses to relational interactions (Stalker 1998). This was certainly the case in this study. Keith had a very emotional response to the manner in which he had been treated in some relationships. For example, he describes being treated as “an orphan” by a particular service. He seeks approval from his circle, and describes not wanting to be disappointed describing lack of contact with one service in the circle meeting transcript which follows:

T9. Sharon. “Ever since the restructuring.

Keith. And that’s taken years.

Charlotte. But he should have been part of that restructuring. If your part of their family, as they said.

Keith. Well I feel like an orphan (laughing). (Everyone laughs). But the main thing I am worried about is disappointing you two (pointing to Sharon and Tom).

Sharon. Now the only thing that concerned me, was that you would be disappointed if you lost (name omitted).

Keith. But you now know I won’t lose (name omitted).

Dawn. You won’t lose it for that reason. They don’t know what you are using those hours for”.

Keith’s family is particularly important to him. He states on numerous occasions that he doesn’t want to let his parents down. It is interesting to note that Keith considers his family as his mother, father and himself. He does not include his brothers. This is because they don’t treat him as an adult, and constantly let him down. He won’t have them in his circle for that reason. This illustrates an important factor in relation to having people in his circle that will not let him down, and will do what they say they are going to do.

His mother has been his main carer for many years, and his father is especially significant to him. Keith looks up to his father and follows his example. This is very clearly communicated in the extract below:

K20. Chris. “What way have you become close?

Keith. Well we just ring each other up we're not in each other's pockets all the time, we don't get fraught or shout at one other very often. We just have a general chat, and he's told me stuff about other family members that's quite good. He never used to discuss things like that with me. Now we have a serious chat. Sometimes he will come over here and watch a big football match with me".

All of the circle members recognise how important his parents are to him, especially his father. Charlotte, Nigel, Janet and Dawn all indicate that he looks to them both for advice, guidance and practical help. He still phones his parents three times a day, even though he has his own flat. Keith hates to disappoint anyone and his parents in particular. Keith and the circle members recognise that his relationship with his father and mother has changed since he moved out. He describes it as not getting fraught or shouting at each other. He also has serious talks with his father especially about family matters that they have never really discussed before. His father visits Keith's flat, and watches football with him. Some of the circle members have also noticed that his relationship has changed. Not only is he more independent and self reliant, but his parents have taken advice from Keith. Perhaps they now view their son as an adult in his own right. Sometimes people's views of a person with a learning disability can be influenced by social factors, for example being viewed as an eternal child, in need of special care (Wolfensberger 1972), or as a sad case to be kept closeted within the confines of the charmed circle (Goffman 1961).

In Keith's case he is valued socially by all the circle members and his parents. His relationship has changed with both. His parents view him as an

independent man who has his own home and circle of friends including a girlfriend. The circle members view him as someone who they want to spend time with and many describe him as a friend.

Keith views the circle members as like-minded people who like to have fun, are cheerful, and not too serious. He sees the casual approach as very important. They also know him well and know what he likes and dislikes. Another important factor is that they listen to what he says, and “don’t nag him to death”. This aspect of person centred planning is very important. Only by carefully listening to the person’s wishes, views and aspirations can a fully inclusive approach be taken (Pealer and Landis 2002; Smull and Sanderson 2004). It is interesting that there are no professionals officially represented in Keith’s circle. Some of the circle members are professionals, and two are employed in that capacity, two are retired. All attend the meetings in their own time. Occasionally other meetings are arranged with professionals and others, for example his social worker or support carers. These only occur when there are particular issues that need addressing. There does not appear to be any issues related to professionals taking control of the meeting. This can sometimes occur when professionals are involved in supporting people with learning disabilities. There also does not appear to be any role confusion either from the professional’s perspective, or those of other circle members. Indeed most members value their professional knowledge and expertise, which is sometimes not the case (Beattie, Gott et al. 1993; Needham 2011).

There are issues related to professionals attending informal gatherings such as circle meetings that require further discussion. One issue appears to be related to how a professional is defined. Parkes and Jukes (2008) defined professionals as

individuals with a professional qualification, but also include within the context of increasing personalisation of services support workers. They also make a distinction between a professional relationship and a friendship relationship. The main difference being that a professional relationship is based on employment, whilst a friendship is not. This relates to the findings in this study where a distinction is made between paid and unpaid professionals (see Keith's relationship table on page 137). He has 8 paid professionals in his life these include doctors, social workers and learning disability team members. The 6 unpaid professionals are all circle members who he considers friends. None of them are paid to attend Keith's meetings. He now understands the difference between unpaid professionals who attend his meetings as friends, and paid professionals who support him with specific tasks. Friends attend because they want to be there, paid staff attend as part of their employment.

Another concern is continuing professional development, since all professionals are required to maintain and develop their skills and knowledge through a process of continuing professional development. This includes attending relevant courses , and keeping abreast of research in their respective fields (Audit Commission 2001). His professional circle members keep themselves updated and coming from a variety of different professional backgrounds have a wide range of skills and knowledge that can be used to support Keith. Keith acknowledges this in his interview when he talks about individuals "making a lot of sense". He also mentions it is important to have "likeminded people supporting him". I believe he is referring to having people supporting him who share common values and attitudes. This is a view shared by his circle members indeed Charlotte mentions that everyone "all think the same". Jowett and Wellens (2000) stress the importance of having a shared philosophy and key purpose in their study describing the development of

occupational standards, for learning disability multi-professional teams. These are based on promoting basic human rights, including the principles of fairness, equality, dignity, respect and autonomy for everyone. These principles are so often lacking when people with learning disabilities are supported, and they were particularly highlighted in the recent investigations described in the literature review of this study including Six Lives (Local Government Ombudsman 2009).

Keith's circle members utilise signposting by directing him to existing services rather than providing services themselves. For example he was encouraged to have a health check at his surgery, supported by a circle member. Charlotte states when describing Dawn's support " she doesn't do for him", but goes with him and encourages Keith's self advocacy and community integration as a result. The group also do not consider themselves as "the font of all knowledge", and frequently call on other professionals to attend meetings when Keith's needs change ,or require particular assistance.

The relationships in this circle illustrate that Keith's parents are very important to him, and he looks to them to guide him in everyday life. He moulds his behaviour and aspirations on those qualities he admires in his father, particularly his ability to problem solve and deal with difficult situations (since he was a policeman). Although he does allude to occasional conflicts when living at home, due to " living in each other's pockets". He also gets assistance from his circle members, and everyone uses an informal approach offering advice, support and information when required. It was interesting to note that the professionals in this group not only attend in their own time, but their advice and guidance is valued by Keith, his parents and other circle members. Individual's personal qualities are very important to Keith and his circle members. These will be discussed in the following section.

PERSONAL QUALITIES

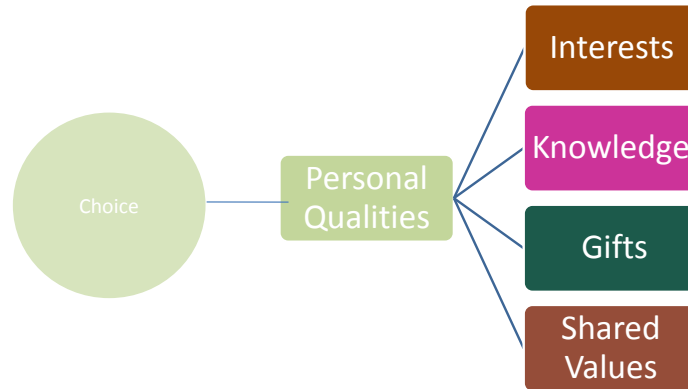


Figure 9. Personal Qualities thematic relationships.

Personal qualities are a very important factor in person centred planning. To many planners they represent the qualities that draw people towards an individual. These have an important role in promoting inclusion (Pearpoint, Forest et al. 1993). By recognising individual values and accepting that each person has unique qualities and contributions to make, irrespective of any labels or disabilities. The person is recognised as a person, afforded personhood and recognised as an individual. This results in the promotion of social integration, the development of friendships and mutual co-operation (Pearpoint, Forest et al. 1993). In this study personal qualities were linked with interests, knowledge, gifts and shared values (see **Figure 9**).

Keith's personal qualities were very well described by the circle members. He has become more assertive. He is an active self advocate who, although hating conflict of any sort, will now stand up for his own rights. However, the circle value

him as a person, and he has developed shared interests that have resulted in him building relationships outside of the circle. The extract from Sharon and Tom's interview describe how an interest in modern history has helped Keith form friendships with the older people living in his shared sheltered accommodation.

S9. Tom. " He has slotted in there very well he likes old people Chris he always has. He will sit and talk the hind leg off a donkey .He said to me the other day by talking to some of them they tell you what they were upto in the war. He said it's fantastic some of the stories they tell him.

Chris. Yes, that's a particular interest of his isnt it?

S10. Susan yes it is and he does go and play wii with them, he goes in the upstairs lounge where they have wii.

Tom. I think personally they have gained by having Keith there. He is an asset as opposed to anything else".

Keith is able to facilitate his own meeting, not only interrupting people when someone also wants to talk, but he also restarts the meeting when people are engaging in general conversation. However, the group give him advice without telling him what he must do. Listening to what he has to say, is particularly important to Keith. He also thinks he controls his meeting well, and brings people around to his way of thinking. He also admits to being cynical about meetings to begin with, but now would not be without his circle. He is particularly pleased with the way the circle supported him with a particular situation. This was when he was excluded from using learning disability services because a member of staff assumed he did not have a learning disability:

K25. Keith. “back in the long distance past yeah, we had an incident about 18mths ago when we all locked together, and were rock solid and sorted the whole thing out.

Chris. do you want to explain what the incident was?

Keith. Basically someone in (service name omitted) decided I didn’t have a learning disability”.

He describes the group as locked together, rock solid, helping him clear his name. It is very sad to reflect that services still treat people in this manner. Unfortunately, when a resource- based service model is used, as opposed to a person centred approach, individual resource rationing takes precedence. This has much in common with the medical model (Foucault 2007) of service provision and other institutional ways of managing people (Wolfensberger 1975; Wolfensberger 1984). This incident will be discussed in greater detail under the instrumental authenticity section of this discussion, but it deserves mentioning here as it is one of the major barriers to effective person centred practice (O'Brien and Lovett 2002).

In addition to having likeminded people in his circle it is evident that all members share the same values. This is particularly true when one examines the terms the group use both within the meeting, and their individual audio interviews. Many of the group fully support an inclusive, emancipatory paradigm, when considering the ways in which people with learning disabilities are treated. Charlotte in particular is very critical of any labels, or the way services treat people in institutional ways. She describes the labels given by one service as “prison talk”,

when Keith describes wings and officers, a view supported by (Wolfensberger 1975). Keith's parents describe the other professional members of the circle as knowing far more about who to contact, and where to go in order to get the right help and support. This is where individual knowledge both in terms of people, places and services is useful. What is important about the way this circle works, is that they have developed a conviction that Keith (and other people with a learning disability) have the right of an ordinary life, living within their local community (Wolfensberger 1972). Also the right to participate and enjoy all the rights and freedoms every other member of society enjoys. They have developed a culture of shared values and beliefs, and genuinely wish to improve Keith's life. This is in direct contrast to services which operate in a paternalistic, resource allocation model of service design ,where individuality and flexibility are stifled by professional control (Brechtin and Walmsley 1989). Unfortunately cost- efficiency savings often lead to lack of resources both in terms of skilled people, and the lack of resources in terms of materials, equipment and time. The result is an increasing number of abuse investigations and not just in learning disability services. The recent NHS enquiries in North Staffordshire are an obvious example (HM Government 2013). There is also another important factor to consider. The move towards individualised funding and care should mean that paying customers such as Keith would be free to purchase what services they would like. There is little competition in the market of services supporting people with learning disabilities, something that the original Community Care Act 1989 sought to deliver (Walker 1993; Baker 2000). Many services are unable to provide a truly innovative and flexible approach because legal and service requirements get in the way, for example Keith is still unable to use his electric wheelchair because service staff have not been trained in moving and handling

(O'Brien 2001). These issues significantly affect Keith's ability to develop his interests, promote a vision of shared values, and positively acknowledge his individual knowledge, and develop his skills in this area. They also actively prevent him developing his own trust in services. Some of these were highlighted in the thematic analysis in particular, negative values, treatment and support, labelling, lack of power and autonomy (individual power and control), and vulnerability. Indeed Keith is vulnerable as evidenced in a discussion at the circle meeting when advice was sought regarding a member of staff changing the temperature on his shower. Keith appeared more concerned with not hurting the staff members feelings, rather than acknowledging that her actions could cause him harm. The extract below illustrates these points.

T12.Keith: "Trouble is, if I say it too firmly she bursts into tears. She hasn't got a lot of confidence. Dawn: That's really not your problem. Janet: No it isn't, she's being paid to deliver the care properly, and safely. Keith: There's a lady called (name omitted) that me and Susan like, isn't that right Susan? (Susan continues reading her book). Dawn: Has the manager read your care plan? Keith: Not yet. Dawn: Well it might be good, to ask her to sit down and read it. Kevin: There's (name omitted) and (name omitted), and they are brilliant aren't they Susan?(Susan laughs when Keith waves at her).

T13.Nigel: Do you test the water before you get in? Keith: Urrh well, not eally because it's at the right.....Nigel: If the girl is fiddling with it, you need to test it before you jump in. Sharon: I always used to do it for him, before he got in. Janet: Is that in your care plan? I like the temperature

on that mark, and nobody touch it”.

These negative values and ways of treatment are in direct contrast to those suggested in person centred planning. However, it is important to recognise that every individual has negative values and feeling which are often not expressed but are internalised. These are often the result of individual experience and reflect part of being human. Sartre would view these simply as acts of bad faith in that the individual is choosing to take these negative values and develop a negative personality as a result (Sartre 2008). It has certainly affected Keith’s view of himself as “worthless”, and results in him being reluctant to engage with services, and support workers in particular. This is directly the result of past experiences. He is frequently let down, disappointed or taken advantage of. As a result he turns to his circle for advice and support. The following extract from the circle meeting illustrate Keith’s frustrations.

T4.Keith: “I just feel do I want to put myself through all that disappointment again. Susan: It’s up to you. Dawn: What they want is (name omitted) to go around all the (name omitted), and do safe places because they want me to do it with you. But that is not how we work, they need to pay us and they are not prepared to do that, so they are trying to do it without paying us. They need to support your transport, support you with somebody when you are there, make sure you have got the equipment you need, and PowerPoint presentation, and that all sorted out. Keith: But they won’t do that. I just want some advice from you guys I think we should take a vote on this”.

An area of particular concern is the lack of acknowledgment of Keith's gifts, by services and professionals. These are the qualities that make people want to be with him, and work to help him get the life he would like. Many of these have been produced in his person centred planning graphics but they include the following qualities (see **Appendix 5**):

What people like and admire about Keith.

He is happy, comical, funny, a chatterbox, sensible, determined and adventurous, caring, tell people how he feels, knowledgeable, entertaining, good memory, good at spelling, generous, good laugh, good friends, and happy go lucky.

Keith's gifts (his own perspective)

Dancing, singing, speaking up in meetings, confidence, getting on with people, lovely smile, planning, talking.

There is also a degree of reciprocity in identifying individual's gifts. Keith's for example admires Dawn's qualities in the following extract:

K23. Keith. "One thing I noticed was the way Dawn came across. The oasis in the whole storm like. Nothing seemed to phase her or anything.

Chris. What do you mean the oasis tell me about that?

Keith. She always seems to diffuse the situation, and make it a lot calmer than what it could be you know. The way she puts things across I mean.

Chris. Tell me about the way she puts things across?

Keith. Just calmly and soothingly she doesn't put people backs up.

Chris so she gives you good advice?

Keith Yeah".

Person centred planning involves a continual process of careful listening, observing, guided discussion and shared problem solving. Clearly Keith is able to reflect not only on his own qualities, but also those of his circle members (Mount 2002). However, the way he has been treated in the past and currently by services, results in him developing a view that he is "worthless" as evidence in one of his person centred plan graphics. This in turn discourages him from engaging with services, spending a great deal of time at home. Fortunately, his circle have encouraged him by acknowledging and promoting his personal qualities and gifts. These are very important factors allied with positive support, which will now be described.

POSITIVE SUPPORT

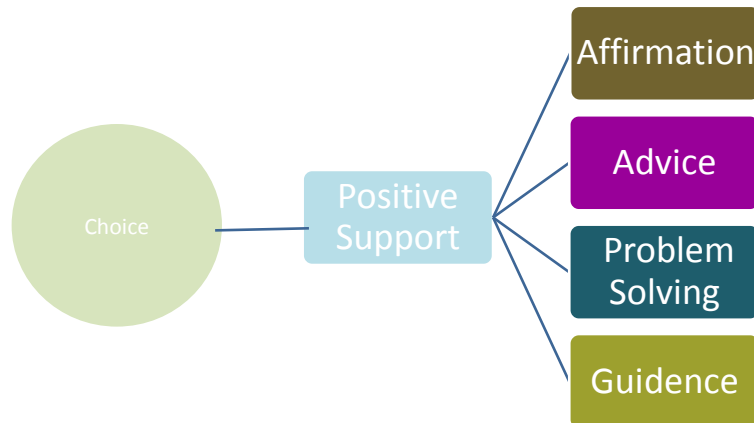


Figure 10. Positive support thematic relationships.

One of the key components of any person plan is to always plan in a positive way, a view supported by (O'Brien and O'Brien 2002). In reality this can be a very difficult thing to achieve since people with learning disabilities are often given negative labels and reputations. People concentrate on deficits, and use professional terminology such as challenging behaviour to describe what people are unable to do. An oppressive, paternalistic relationship is unlikely to get people the life they would wish (French 1996). This correlates with the findings in this study where positive support was linked with affirmation, advice, problem solving and guidance (see **Figure 10**). Keith's circle reinforces these concepts. It uses positive terminology at all times, constantly encourages, and supports Keith and other circle members (Mattingly 2006). They give constructive advice and guidance, and have developed a

joint approach to problem solving that is very effective. The following extract from his circle meeting transcript illustrates these points effectively:

T7 Dawn: "This is part of your training Keith, it's about getting them to know how to support you in the right way. It's not just about ticking a box. Keith: The day I was supposed to do the training, I was called away to a presentation, and really I need not have been there. If they want me to do the safe places, I am going in blindfold as I was called away on other jobs. Dawn: I can support you with safe places, we can put a PowerPoint together that's a really easy part of it, but they need to make sure that they support you to deliver it, and they support you in the right way. Keith: Charlotte said the right thing they should pick me up and help me out with this. Charlotte: Yes they should. You are doing them a favour. How many (name omitted) have you got there that don't get paid. Everybody gets paid, you don't though. Dawn: All you are asking for is a little bit of respect, you're not asking for the moon".

Dawn introduces the concept of affirmation to describe the way the circle constantly encourages and guides Keith to make his own decisions. This is an important finding and new, but fully supports positive support by encouraging joint decision-making, and self advocacy for people with learning disabilities (Binns 1998). Keith also recognises that he "gets good advice" from his circle and "they talk a lot of sense". He also understands the concept of problem solving. He describes it in the following way:

K13. Keith. “I don’t really know, I guess it’s trying to problem solve.

Chris. and what does that mean?

Keith. It means you’ve got a big problem, and you are trying to diffuse the main problem. You are trying to get rid of the nuisance, or look at or give a different approach in other words”.

I think Keith means that the group look at different perspectives, and together give him other options that he may not have considered. He then makes the final decision, and the group support him in that. An example was the way he made the decision to attend the meeting with a service provider with Dawn. At the meeting he told them how he felt, and the matter was resolved to Keith’s satisfaction. There was a great deal of group discussion on this issue in the circle meeting. Keith repeatedly stated he didn’t really want to be let down again. The group offered a solution in arranging a face- to- face meeting with support, and Keith made the final decision, without any pressure from the group. His parents supported the decision. As his father Tom stated “ it’s your life you must do as you want”. This clearly is a very liberating relationship with the group for Keith, and also for the circle members who all enjoy attending and look forward to the meetings (Gomm 1998). It also encourages the development of control over ones destiny which is the next theme described.

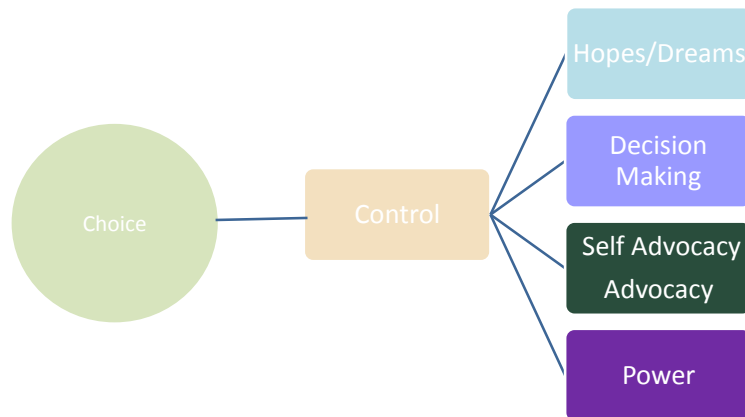
CONTROL

Being in control of one's life is a very important part of defining one's self as a person. In the most extreme of circumstances people will act in a number of different ways. For example, during the holocaust when individuals lose control over their destiny, they take two main courses of action. Firstly they give up all hope, become down trodden and hopeless. Secondly they fight against the extreme circumstances, determined to survive and bear witness (Bettelheim 1943; Levi 1998). People with learning disabilities have had to endure being treated in such a manner even today (Wolfensberger 1984), and Keith is no exception (Department of Health 2012). Being in control is a very critical part of the process of person centred planning (Mount 2002; O'Brien and O'Brien 2002). In the case of this circle Keith is in control of his circle as he chairs the meeting.

K1. Keith. "Well first of all I thought I was controlling the meeting well, um well obviously we were trying to sort out a problem mum had her view I had mine. I thought it was a bit of a battle there, but we managed to sort it out between us. Mum was sort of saying I couldn't have me day out and I thought, well I can if the (name omitted) want me they will have to provide transport and stuff".

The group assist Keith in making choices through a number of sub- themes, these were generated from the data. These will be individually discussed in this section. These can be seen in **Figure 11**.

Figure 11 .Thematic relationships relating to Control



Very closely linked to control is the idea of power. If someone feels powerless then it is unlikely they will have any control over the way they live their life, or any other decisions they may wish to make. (Gomm 1998) describes four types of power relationships:

1. An oppressive or liberating relationship where services are viewed as objects of oppression. They provide misinformation in the form of expert opinion exploiting the powerless and poor. They insist the world is a fair place and those who have problems have only themselves to blame. In this capitalistic, Marxist model the service users are defined as objects of oppression to be manipulated for their own good (Fromm 1973; Sartre 2006).
2. A disabling relationship. Services and agencies, including those who work for them, are viewed as exploiting those they serve for their own benefit. The problems of service users provide secure and well paid employment

for the workers. The services define how the services develop, and the workers know what is best for service users. They closely defend any changes to the service boundaries and such a paternalistic model is heavily linked with the specialised, medicalised model of service provision.

3. A brokerage relationship. In this relationship the workers are viewed as brokers between the service, users and the community. They negotiate the best deal for the interests of the service and the user, often playing the needs of one off against the other.
4. A helping relationship. Here the workers who are experts in the field (practitioners). They help service users identify what they need, and assist them in ways that they would be unable to do themselves. Workers claim to know what is best for the people who use the service. The practitioners will know what to put right with matters concerning the service.

In the case of Keith's circle group there is no clear fit with the power relationships described in 1 and 2 above. The relationships the group use are a combination of 3 and 4. However, the group use a shared decision-making process they have developed to assist Keith, and he always makes the final decision. I have deliberately avoided using the word empowerment in this study, except when quoting others. This is because it is often linked with someone (usually a professional, carer, family member or other authoritative person) holding power over the person with a learning disability. If one's view of individual empowerment means seizing control of power, and liberating oneself from the shackles of oppression, then there is no need to use a different word to express this concept. Often empowerment is viewed as a professional gift without any

serious consideration regarding the implications for the individuals, or groups involved . It involves devolving the gift of power to someone else (Freire 1993). (Flatt-Fult and Philips 2012) support this view considering empowerment to be a struggle for people with learning disabilities. They describe an individual's lack of power because of social exclusion, poverty, abuse or services not meeting their needs, as contributory factors. They highlight the need for staff training, knowledge and mentoring people with learning disabilities to take control over their own destiny. In order to achieve this, individuals need support to specify what they need in their life, support to identify, locate, access and take control of their preferred options, and finally, support to help control and influence the resources obtained (Stainton 2005).

Empowerment can be viewed as a very complex matter amalgamating a number of interrelated factors linked to social exclusion and emancipation, rights, choice, citizenship and knowledgeable support and assistance. It really embraces the concepts of liberation and social and civil emancipation. These are factors that have also been highlighted in Keith's circle. His group have developed a method of working together with everyone treating other members as equals with their own contributions to make. No one uses the gift of power over anyone else. Indeed those who are employed as professionals attend planning meetings in their own time, and are not representing services they work for at meetings.

Interestingly, the findings in this study resulted in a demotion of the hopes and dreams to a sub- theme. All of the literature related to person centred planning emphasise the importance of hopes and dreams as providing a fulcrum to guide the planning (Pearpoint, O'Brien et al. 2001; Falvey, Forest et al. 2003). This did not take

place in this group. In fact only two people mentioned dreams at all, Charlotte and Keith in relation to him going to Hawaii.

K27.Chris. "You mentioned we have been to Hawaii twice what did you think about that?"

Keith. Excellent I would go again tomorrow if I had the chance. It's really paradise on earth.

Chris. And what did you do there then?

Keith. We talked about health facilitation in (name omitted) the first year, and person centred planning the second year. I think we both preferred the second year 'cos we had a bit more time, and we could do what we wanted, seven days was a bit much. It was a good experience and I was glad I went.

Chris. And that happened because it was one of your dreams?

Keith, Yes basically I am very lucky I am a trend setter".

C33. Charlotte. "It was the thing of his life that.

Chris. But that happened because I was in the circle and knew he wanted to travel.

Charlotte. He will have that for the rest of his life.

Nigel. it gave him huge confidence too knowing that he could do that.

Charlotte. Yes taking him to the Chip shop pales somewhat into insignificance . (Laughter)".

However, as Charlotte and Nigel state, it was a very important part of Keith's life giving him the confidence to do other things. It is possible that at this particular circle meeting, the discussion of hopes and dreams was not a prominent part of the conversation.

One of the key areas for Keith and other people with a learning disability is advocacy and self- advocacy. Charlotte and Nigel both express the view that Keith has become better at speaking up for himself. This is largely due to the way his circle members support him. For example, they describe how Dawn supports Keith to resolve a meeting with another service who has unfairly treated him:

C21. Charlotte. "Well she supports him but she doesn't do for him, she facilitates him to be able to do things, puts different angles on it.

Nigel. And gives him the confidence to go and be able to speak his mind. Charlotte. She says I will go with you, but you must say how you feel to them. He hates conflict and confrontation it's the last thing he needs. He is growing in confidence and saying things, he is getting there with support. That's what I think it's all about don't you?

Nigel. Yes he's developing his own views, and gradually getting the confidence to express them now, that's what the circle helps him do".

This view of self- advocacy of developing your own views and choices, and speaking up about them is very important (Goodley 2000). It also defines self- advocacy as opposed to advocacy when others speak on your behalf. It could be viewed that this group use both. Most of the time through guided decision- making they encourage Keith to become his own self- advocate. They also advocate on his

behalf within, and outside of the meeting. For example, Janet assisted him in her professional role as a learning disability nurse to deal with an incident with another nurse as described by Charlotte and Nigel below:

C35. Charlotte. “Well there was that thing with a nurse wasn’t there where she asked him about his sex life.

Nigel. Right in front of his dad, totally inappropriate.

Charlotte. Yes totally.

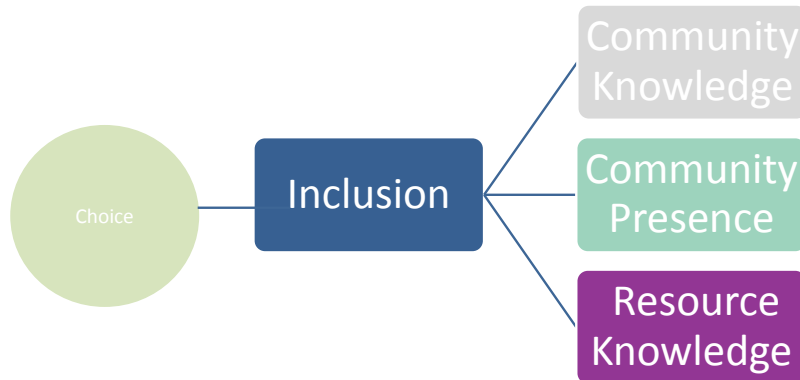
Chris. He was very angry about it but he was supported by Janet and it was dealt with”.

Self- advocacy is also linked with the process of self- determination for those minority groups who have often been denied a “voice”. It is a very powerful part of person centred planning, and fully supports the principle of people taking control of their lives (Goodley 2005).

INCLUSION

Another important theme arising from the data was that of inclusion. It contained the sub- themes of community knowledge; community presence and resource knowledge (see **Figure 12**).

Figure 12. Thematic relationships relating to Inclusion.



Inclusion has proven to be a difficult concept to define. Goodley (2005) defines inclusion as based on the social model of disability where impairments are viewed to be socially constructed and defined. Inclusion rejects the medical model of disability, where disability is viewed as a medicalised problem defined by impairments, to be managed by professional intervention and treatment. (Needham 2011) defines inclusion in the broad context of promoting individual personalisation. This is described as individual involvement, and connection with the local community in which the person lives. O'Brien cited in (Mount 2002) refers to it as the integration, and participation of all people in society. In view of the way the circle operates with Keith, their whole approach to inclusion appears to embrace all of these definitions, but in particular the latter one. This extract from his parent's interview transcription emphasises this approach:

S23. Tom. "He wanted to be like his brothers, that's where the uniform comes in. He is the same as them; it's boosted him a lot. He was so

thrilled he was in a uniformed service. It put him on a par with his brothers.

Sharon. And the page that the Guardian did on him.

Tom. And what you did with him taking him to Hawaii twice helped him learn more. It was alright living here with mum and dad, but he was in an enclosed environment here. He did not go out a great deal he never wanted to go out, not that I wouldn't take him. He just didn't want to go anywhere. Then he started going out with you, and one or two other people and it brought him out of himself. He would do virtually anything now".

He is being encouraged to go out into the community both locally and further afield. This not only broadens his knowledge, but improves both his self- confidence and self- worth. It also encourages Keith's community presence. This is a very important part of changing the community's attitude with regard to people with learning disabilities (Walmsley, Reynolds et al. 1998). However, for community presence to work it has to be a valued involvement, and not tokenistic inclusion (O'Brien and O'Brien 2002). Unfortunately there is an example of this type of involvement discussed in the video of the circle meeting, and expressed by Charlotte in her later interview.

Section C18. Charlotte. "Listening to Keith about this (name omitted), they are treating him really shabbily. They pick him up and drop him, and he is desperate to join as he said he thought he was part of a family,

but as he said he is the black sheep. It's like being treated as a second class citizen there".

Only by talking with, and interacting and living alongside people who have learning disabilities, will attitudes change. As a result hopefully, stigmatisation and discrimination will be reduced (Goffman 1961; Allott and Robb 1998).

If Keith is going to be successful in integrating with communities he needs to know and understand how that community operates, and how to interact with it. The circle of support could be regarded in itself as a community. It is a repository of community knowledge and expertise, since its members have many years of experience in supporting people with learning disabilities, and supporting Keith in particular. This extract from the audio data illustrates this point:

S1. Sharon: " I think they make it clear that they understand and interpret things clearer than we do. Because we don't understand the workings of the departments like they do.

Chris. When you say they who do you mean?

Sharon The members of the group who got the professions that join them into what..... You know the benefits that Keith, that he's getting, and that's a help".

S2. Tom. "I think Sharon and me are both at a loss to a certain degree. We both sat there and listened to the people who we thought knew a lot more about it than we did, and their views to be quite honest. A lot of the

stuff came over very well. Especially with Keith's trips out with the firm he goes out with, what's their name Sharon?

Sharon. (Name omitted to preserve confidentiality)".

His parents are particularly skilled at anticipating and meeting a variety of his needs. Sharon in particular cared for him for many years.

K20. Keith. " I don't know really I guess he thinks mum has done everything for me, and he has kind of been in the background all my life.

Chris. Why because your mum cared for you.?

Keith Yes mum did everything for me basically, but since I have moved, me and my dad have become a lot closer".

The final sub- theme developed under inclusion was that of resource knowledge. This refers to people, places, and materials. Only by intimately knowing what is available locally and how to access it can an individual have a hope of real inclusion (Burke 2006). This group is particularly skilled in utilising its resource knowledge capability to assist Keith (Kemm and Close 1995). This is illustrated in the following extracts:

K16.Keith. "Yes that's how I see the group working, basically they give me some guidance and advice on where I should go next ".

J3. Janet. "Oh Right. Well obviously everybody is there that Keith wants to be there. Presumably they are people whose opinions Keith very much respects and who he works with quite closely. He does look for

guidance from a lot of people who were sat there in that room. Yes so I think, and I think it is very productive and I think it's quite productive for Keith to be able to have everybody in the room and discussing those things that are very important to him and get other people's opinions, for example why are there all those issues with regards to the (Name omitted) and whatever Dawn is saying she has more awareness of that issue, and that's why she is speaking quite a lot. You could say it is because there is more awareness of values and issues because she has students and is picking up quite a lot because of that. She also has more awareness of the issues involved with Keith in the (name omitted) service".

All the group members participate in this sharing of resource knowledge .It not only involves individual expert opinion as in the case of Dawn above, but also includes local knowledge. As a result Keith has developed his own knowledge of resources, and his self confidence has improved.

S18. Tom. "He really came to the fore when he was talking about going away to (name omitted) with the hours and everything else. He is not shy and knows what he is entitled to I think. He went to Dawn who backed up what he said which is what he likes to do. He likes to be backed up on various things he comes up with. I think his knowledge has improved about what he is entitled to because of the circle and the various people he has met. He has come out of his shell to quite a big degree".

CHOICE

Choice, power, and control are often all viewed as linking together to ensure individual autonomy (Department of Health 2001). However, the data in this study did not reflect this, either with regard to the relationships between these factors, or the degree to which they were reflected in the data. As choice was repeated many times during the analysis this was included as one of the core themes, after person centred planning. The connection was made because choice is a major part of how person centred planning is achieved. In the case of this group Keith is constantly given choices in the form of advice, suggested actions or knowledge (specialist and non- specialist). He then makes the final decision on how he wishes to proceed. Sometimes this is with support from his circle members, sometimes he does it himself, and occasionally others agree to act on his behalf. Without being able to choose for himself, it would be difficult to see how Keith could remain in control of his own life via his person centred plan. This is a view supported by many authors. But it is particularly relevant with regard to the theoretical position taken in this study with regard to Sartrean existentialism (Sartre 2007). Keith would be viewed in terms of entering life like an unwritten book. He is free to choose how his life is lived. There is no such thing as a pre-existing concept of self; he goes through life making what he will of himself. In Keith's case he relies on his circle to help assist and guide him, but he chooses to act or not to act himself. In choosing for himself Keith also chooses to act for others. Many of the circle members commented on how kind, and helpful he is to others. He also views himself as acting for other people with learning disabilities, and other people in the community. For example, helping a person with physical disabilities in the extract below:

S24. Sharon. “And I think now he does try to help other disabled people. He is spending his day off next week with a disabled girl who ran away from home. He was very concerned.

Chris. That’s typical of Keith he is a very kind, caring person.

Tom. I don’t think he has a nasty bit in him to be honest.

Sharon. At the time she went he tried to help her mother and father as well he spoke to them on the phone. He coped with it, he wouldn’t have coped a while ago”.

There is also the question of choice with regard to the circle members. All of them come to meetings in their own time. No one is paid to be there in a professional capacity, officially representing a service. They choose to come because they enjoy the experience, and have great regard for Keith. They want to help him achieve his life aspirations. They consider him a person, and treat him as such:

C3. Charlotte. “Oh god no, and I think we all genuinely like each other. You know I am very fond of Keith but as a friend, not as I was once was a health professional and he was a patient, client, service user. I hate names like that. He is a person that’s the bottom line for me, and were thrashing it out”.

CONCEPTUAL MODEL OF ATTRIBUTES

It was never the intention of this research to develop a conceptual model, but it arose as a result of the data analysis. Following the thematic analysis a mode of graphically conceptualising the principle key themes was required, in order to explain

the key attributes of person centred planning emerging from this study (see **Appendix 8**).

A model can be considered as a method of illustrating key concepts, but also the relationships between them (Kundu, Schiro-Geist et al. 2005). It was also important to relate these concepts, and their relationships to the principles of person centred planning highlighted in the earlier part of this chapter. Of particular interest was how these fit within the philosophical positioning developed in this research. It became apparent that the key principle of person centred planning should be central to the model. This was how Keith's circle worked. He was central to any decision-making process, always involved, and what he said was listened to and acted upon. The next central principle was that of choice. No decisions were made without a variety of choices being offered, but the final choice was Keith's. He is undoubtedly in control. This is summarised in Janet's extract:

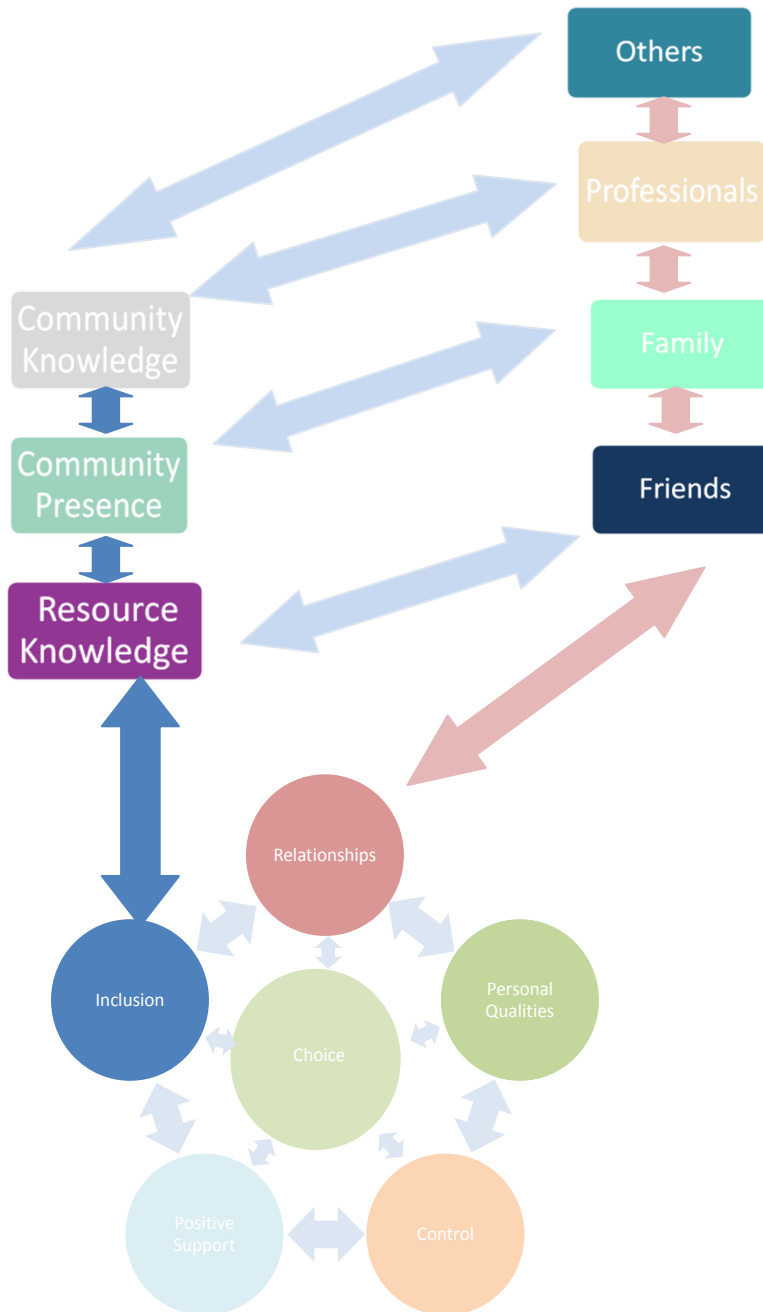
Janet. "Yes he is running the group and definitely running his own circle. He is in control of it , he's invited everybody it's all under Keith's direction. Everything Keith wants to be discussed is being discussed".

Choice was a major component reflected throughout the variety of data used in this study. This included the thematic content of the interviews, the circle meeting, and Keith's graphic representations of his person centred plan. This resulted in it becoming a central key concept, after person centred planning. It also linked with the existential philosophical stance that supports individual self determination, in particular Sartre. When Keith chooses to act he not only chooses that action for himself but also the others members of the group. In particular his parents who he always wants to please, and not let down. Choice is an important part of everyone's

life. In making choices individuals can open up new possibilities for themselves and others.

The development of new opportunities can be illustrated in the conceptual model. For example, fostering inclusion leads to an increased community presence. This results in developing a greater knowledge of what happens in the community (community knowledge). This in turn leads to how to get the help needed to access new experiences in the community (resource knowledge). These can then link with the other themes, for example relationships. Keith regularly goes out with circle members, family and friends and meets with other professionals. In fact the conceptual model is rather an oversimplification as it is represented. At different times in Keith's life, different themes will be linked together dependent upon, what is important in Keith's life at that particular time. These connections are not hierarchical, or arboreal but are rhizomatous (Deleuze and Guattari 2008). This means that some of the connections forged will be lost, others will continue, and some will be constant. For example Keith is developing connections with his community, but his family and friends are constant. He hopes to make new friends in the community, and these in turn will lead to new opportunities. These relationships are illustrated in **Figure 13**.

Figure 13. The Conceptual model and the relationship between the themes of Relationships and Inclusion.



The process in **Figure 13 above** illustrates the issues discussed in the circle meeting. How does Keith develop relationships that promote inclusion? It was used

in the context of a particular service, but the principle applies to Keith's life generally. In order to promote Inclusion a number of main themes are important. Those of Relationships and Inclusion are particularly relevant at this time in Keith's life. Allied to each of these are a number of sub- themes which also have an effect. For example, in order to develop relationships Keith needs friends. Friends can be found in the community, but in order to access them he needs to know where they are located. This is where knowledge of his local community is needed, both in terms of the places where people meet, and what resources are needed in order to access them. For example, how will he get there?, who will pay?, how will he meet people once at the location? The issue is a very complex one, and this illustration is an oversimplification.

In reality all the themes, sub- themes and central themes are inter-related, so arrows indicating connections should be universal. However, I am attempting to illustrate that at this particular time in Keith's life, relationships and developing inclusion in community activities is of major importance. As time progresses other themes will have greater prominence. In this manner connections are lost and gained in a rhizomatic way, rather like a piece of grass pushing through soil. Sometimes the roots grow and develop, sometimes they find obstacles and go no further (Kaufman and Heller 1998).

The conceptual model of attributes has been produced with the intention that it is to be used as a complement to practice. It is not intended to be used as an audit tool, checklist, or quality indicator. These are examples of the debasement of person centred planning where service system values and system rationality take priority over the needs of the individual (O'Brien and Lovett 2002). Person centred planning

challenges service culture by putting new demands on what is traditionally provided. This should be viewed as strength since it often results in new and innovative ways of working. The model embraces this approach, and should be viewed in the context of promoting person centred planning. Also ensuring that those working with a person to plan their life should carry it out with “heart and soul”, and act in an inclusive, valuing and ethical manner at all times (Morey, Redburn et al. 2010).

ETHICAL PRACTICE

Although this has not been included as a component of the conceptual model, it has proven to be a very important part of both this study, and the way the circle supports Keith. Warnock (1998) defines ethics in terms of a public ethics based on the moral principle that all human beings are equal. She also defines a private ethics where there is an inner sense of what is right and what is wrong. There is commonality here with Aristotle’s belief that there is something that sets humans apart from other species, and this is that they can use rationality (Barnes 2000). They can choose to act in a good or bad way, but the choice is a matter of moral character. A person can act in a good way because he believes in acting for the sake of the common good. Keith’s circle choose to act in the way they do because they have a shared belief in acting for the common good, in helping Keith get the life he would like, it is about positive affirmation. The extract below from Dawn’s transcript emphasises these points:

Chris. “I like what you said earlier about affirmation perhaps that’s an important part of being in the circle?”

Dawn. Yes and for me as well if I’m being honest because I work quite

isolated as you do, it's me who is the core at work and all the guys look at me as if I'm some sort of Oracle to be able to solve the world's problems which of course I can't. So I need the affirmation as well from everyone in that group there is a lot of people that know Keith really well, and everybody there has his best interests at heart and is solely there for him. As well I enjoyed that aspect of it. I put things out on the table and make sure that I'm doing it right for him".

The act of doing something for the common good also has a resonance with Levinas's ethical metaphysics (Levinas 2003), which has also been discussed in the literature review of this thesis. The main tenant of this approach is acting for the other rather than acting for oneself. In this way it represents a very humanistic view of ethics. Human interaction should at all times take the form of acting in the best interests of others. This also reflects the way Keith's circle supports him at all times. It also reflects the way people with learning disabilities should be supported, not just in terms of person centred planning, but throughout their life. A common set of ethically based values and attitudes when supporting anyone, should be to all individuals. The UK Government's Dignity in Care Campaign (2009) seeks to address this matter (2009). The Dignity in Care Campaign defines dignity as:

“a state, quality or manner worthy of esteem or respect and (by extension), self- respect”.

Final report of the Department of Health Dignity in Care Campaign,

Department of Health (2009), page 6.

It is interesting to note that a number of barriers to acting in this way were reported as a result of the campaign. This included a general lack of time being the most frequent barrier. This was preceded by lack of understanding, general lack of care and empathy, and finally poor attitude or mindset, of staff. Clearly there is still room for major improvement. However, this research at the very least shows a willingness to really address these issues.

There were also a number of ethical dilemmas that arose from conducting the research with Keith's circle. Keith and Charlotte both expressed concerns regarding confidentiality. Keith in particular required constant reassurance throughout the research, and I made myself available either by telephone or face- to- face to answer any concerns. The following interview extract illustrates some of these concerns:

C39. Charlotte "and that it's confidential.

Chris .obviously this stuff will not be shared with anyone, the DVD Keith will have but the audio tapes will be destroyed. There are some things discussed I will have to handle carefully as I would not wish to compromise anyone, but it's important to include some things for the research".

Following this reassurance Charlotte and Nigel gave full permission for any part of their interview to be used.

However, the stance any researcher should take is to do no wrong and never harm anyone participating in the research (Silverman 2003; Robson 2007). This view supports Aristotle's view of a virtuous ethic, and promoting actions and relationships that foster the best qualities of being human. These include, being great souled,

liberal, courageous and virtuous (Mac Intyre 1998). It is often helpful to reflect on how one would like to be treated oneself, when considering ethical decisions of this nature. Levinas (2003) conceptualises this very well in an awareness of others suffering or vulnerability. Also having an empathic ability to act to alleviate this suffering in others. There is also commonality here with regard to the authenticity of person centred planning. The way plans are carried out with people, rather than on them is a prime consideration. Levinas warns against the “Thingification of man” in this way (Levinas 2001). Let me in I’m a Researcher (2006) describes ethical research as:-

“ treating everyone with care and respect . It is also important that the research should empower people, not put people down”

Let me in I’m a researcher! (2006), Pg 47.

This document also goes further and illustrates how people with learning disabilities are now challenging the view, that research is the domain of experts. They wish to be viewed as experts in their own right, not as passive subjects or unpaid advisors. This view fully supports the professional gift model which dominates the field of learning disability research, and disability research (Gomm 1998; Goodley 2000). It is often supported by the use of negative labels where the experts take ownership of the person for example, client, patient, or special needs. This results in an unequal relationship with regard to power, control and status (Holburn and Vietze 2002). It also results in ethical practice being viewed as a method of defining problems produced by the judgement of researchers, and the “industry of

educational research” (Bayliss and Thoma 2008). Charlotte describes this very well:

C1. Charlotte. “It’s so good for Keith and we are all equals, because so often in health and social services people who have been deemed to have a learning disability, I don’t like that term, are the lower in the partnership. In our circle there is you Chris, me, Nigel, Dawn, Janet, Mum, Dad, Susan, it really is just a group of friends”.

The reason for this negative treatment is grounded in a culturally adopted belief that people with learning disabilities are unable to consent, because of an assumed cognitive impairment (Goodley 2000). For an individual to be able to give informed consent they must understand fully what decision they wish to make on a given matter, taking fully into consideration all the information available (Department of Health 2001; Department of Health 2005). Obviously judgement has to be made in this matter by the person, but they need to have information presented in a format that they can fully understand. This may involve the use of specialist pictures or symbols, or photographic representations of objects or procedures as objects of reference (MENCAP 2000; Poncelas and Murphy 2007).

In the case of this research a variety of accessible information about the research was provided, including an information sheet, and a consent form (these can be seen in **Appendix 2 and 3**). However, the way this circle works is to openly discuss any matters, and encourage Keith to reach his own decisions. I fully embraced this methodology as it was very inclusive. Additionally, the group had successfully been utilising it for many years. Rather than viewing Keith with a deviant or negative label the group use a personalised practice. This takes the form of

discussion, social interaction and action (Gill and Maynard 1995). This view of personalising an approach based on the person also fully supports the principles required for person centred planning and person centred approaches (O'Brien and Mount 2005) .

AUTHENTICITY IN PERSON CENTRED PLANNING

Authenticity is a critical episteme in this thesis since it is directly related to the research question in this study How authentic is person centred planning? Defining authenticity is problematic since it encompasses many inter- related concepts. Many of which are philosophical in nature. These have previously been discussed in the literature section. However, I wish to illustrate both the complexity involved, and the interrelatedness of the concepts as a result of the findings in this particular circle of support. As with the discussion of personhood it may be more effective to examine inauthentic examples as they relate to person centred planning, but I would first like to consider the essential nature of authenticity in terms of its basic definition.

In philosophical terms authenticity can be defined in a number of different ways, depending on what particular school of philosophy followed. All have a number of features, or properties that signify authenticity. Since this research is based within a framework of phenomenology and existentialism, it is important to examine the essential features of both briefly (there is a detailed discussion of both phenomenology and existentialism, and in particular the work of Husserl, Levinas, Sartre and Heidegger in the literature section). Phenomenology concerns itself with how human beings make sense of the world they inhabit, and how they experience it through conscious and unconscious acts of perception. Existentialism concerns itself

with how the individual defines his or her own sense of being, within the context of being in the world (Lemay E and Pitts J 1994; Levinas 1996; Sartre 2006).

Authenticity can be defined generally as the state of being true or genuine. Thus to be authentic, an object, or person has to have certain qualities or features that enable it to be classed as genuine, truthful or proper (Chambers 2006). It applies to a variety of different fields for example, philosophical thought, anthropology, creative writing, art and music.

The composer Philip Glass describes his introduction to Indian music which illustrates defining authenticity in greater clarity. Glass was employed to transpose Ravi Shankar's music into Western notation. As an experienced composer and orchestrator he used the same principles he was taught in Western notation. He was unable to reproduce the music to Ravi's satisfaction. Eventually he realised he could not use a Western bar line. Indian music consists of rhythmic cycles or "Tals", and all the notes are equal unlike Western music (Glass 1987). This also illustrates the difference between nominal and expressive authenticity as described by (Dutton 2003,).

Nominal authenticity can be determined by confirming that the object, person or concept is what it purports to be. So Indian and Western music are both forms of music and have certain nominal characteristics. Expressive authenticity is provenanced by the object, person or concept itself; essentially it is true to its own nature. Thus Indian music differs from Western music in the way it is played and written, because it has its own distinct and particular qualities.

In the case of person centred planning irrespective of the type of planning used or the focussed person, there will be certain nominal characteristics common to all. However, there will also be a number of distinct differences that relate to the

individual person, what aspirations and challenges they have in their life at the particular time planning takes place, that are distinct only to them. Many of these have been highlighted by this research conducted within Keith's circle. Some are very specific to Keith at a particular place and time. For example, Keith:

T7. Charlotte. "They just can't pick you up, and drop you.

Dawn. If they want you to do the safe places, obviously I will work with you to develop the presentation, but I am not going to do it with you. If Keith is part of the team they need to take some responsibility.

Charlotte. Yes part of the family".

Others are universal and can be applied to everyone taking part in person centred planning. For example, Keith mentions problem solving in this extract from his interview transcript:

K13. Keith." I don't really know, I guess it's trying to problem solve.

Chris. And what does that mean?

Keith. It means you've got a big problem, and you are trying to diffuse the main problem. You are trying to get rid of the nuisance, or look at or give a different approach in other words".

However, both contribute to defining the authenticity of person centred planning.

Bank (2013) also describes Instrumental authenticity which can also be

applied to person centred planning. This is a variety that has similarities with expressive and instrumental authenticity, being intimately linked to the social and cultural situation in which it occurs. For authenticity to be instrumental some person, group or organisation uses authenticity as a means of achieving a benefit. This could be material, political, corporate, or any other way in which agency is used. It could be suggested that many of the United Kingdom Government's policies produced highlighting person centred planning are instrumental in nature (Department of Health 2001; Department of Health 2009; Department of Health 2010).

With regard to the authenticity of the planning that takes place within this particular circle, one also needs to recognise that authenticity refers not only to a cultural construct, in this case the circle of support (Handler 1986), but also to what constitutes the "truth" for the individuals involved (Van de Port 2004). The result generally for this group of individuals is that person centred planning is authentic. The group members firmly believe that it has transformed Keith's life, made him more confident and independent and resulted directly in him moving out of the family home to his own flat. It has increased his community presence, and Keith is particularly proud of being a "trend setter".

This supports the findings in the only large scale longitudinal study of person centred planning conducted in four areas in the UK (Robertson, Emerson et al. 2005). There were significant improvements in the quality of life for people, and their social contacts. Their contact with family members and friends increased, and the number of community activities also grew. It also resulted in a massive increase in choice for individuals (Sanderson, Thompson et al. 2006). What this study did not

show was how the planning takes place, or what is required in terms of group members' backgrounds, personal qualities, relationships, or how in control the person is throughout the whole process (nominal authenticity). It also did not examine the person's dreams, gifts or aspirations, or examine any hidden meanings in the form of essences or what constitutes truth (expressive authenticity). It also failed to represent any benefits that could be gained either by internal or external agents (instrumental authenticity), with the exception of costing the process of person centred planning.

The individual types of authenticity will now be analysed since these are a critical factor in answering the research question posed in this study. In order to evaluate how authentic person centred planning as a method of planning is, one has to understand the different types of authenticity, and how they relate to this study.

NOMINAL AUTHENTICITY

This form of authenticity has features common to all types of person centred planning. The work of (O'Brien 2002) illustrates this when he considers five accomplishments which are very important features of authentic life planning for people with learning disabilities. These are as follows:

Community presence, without this the person leads a life excluded and often secluded in institutional settings.

Choice, this is the growing of personal autonomy from small personal matters to larger life changing decisions. Many people with learning disabilities are judged incapable of making their own decisions, and have to rely on guardians, or advocates to do this for them.

Competence, This is defined as the ability to skilfully perform meaningful and purposeful activities. Valued activities help define the person's individual and social interests.

Respect, This is having a valued place among a group of people which could be a community or an individual's home and family. Often people with learning disabilities are confined within stereo- typed negative roles e.g. employed in repetitive ill- paid work.

Community participation, This is being part of a network of personal relationships which includes close personal friends. Often people with learning disabilities have small networks confined to paid staff or family members.

Each of the accomplishments are closely linked to the others, and can work with, or against each other. This is very similar to the manner in which the themes developed in the conceptual model produced in this study. Certainly the data gathered from Keith's circle supports these views. With regard to community networks the research illustrated that he had very few non- professionals, or other paid staff in his network. However, the way they supported him ensured his views and choices are encouraged, developed in a positive way, and acted upon as this extract from the circle meeting demonstrates:

T5. Dawn. "This is just a suggestion shall I speak with (name omitted), I know we have done this before but I'm happy if we go and have a conversation with him, but you need to be really honest and tell him exactly how you are feeling.

Keith. I feel used to be honest.

Charlotte. You need to get a contract with him.

Keith. Trouble is I don't like to go in all bolshie.

Dawn. It's not about being bolshie, it's about being honest and I think they need a dose of honesty. I think you are within your rights to say you are disappointed.

Charlotte. You'd do ok if Dawn was with you.

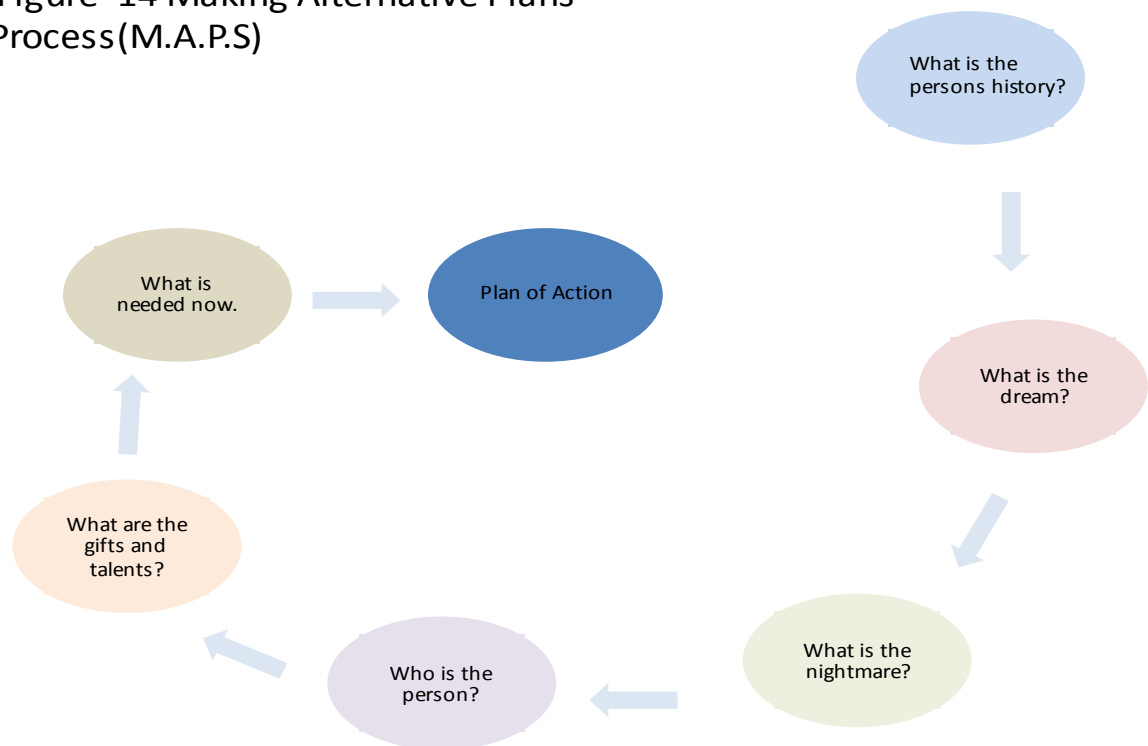
Keith. Yeah".

Keith's circle also support him to participate in valued activities. As a result the circle members report that he has not only developed competence, for example in training others, acting as an advocate for the elderly, and other people with disabilities. He has also developed new social interests, for example attending pub quiz nights, and going on holiday with his girl friend and other circle members. Although Keith has experienced services trying to confine him within stereotyped roles, for example the token person with a learning disability in a particular service. He has also gained the respect of not only his circle, but family members. Indeed his mother Sharon expressed a need at the end of the meeting, to celebrate her son's many achievements. Keith is developing a wider support network, but has developed personal relationships with many of his circle members. Most now consider him as a friend.

There is also a parallel with the positive changes noted in Keith's life with the changes required for personal futures planning to occur (Pearpoint, O'Brien et al. 2001; O'Brien 2002). These are changes in the person, change in the services that they use, and finally change in the use of community values, and community services (O'Brien 2002).

Many of the processes included in Keith's circle can also be seen in developing M.A.P.S. **Figure 14.** Illustrates the main requirements, this was adapted from the original to reflect the findings from Keith's circle meeting, and other data collected.

Figure 14 Making Alternative Plans Process(M.A.P.S)



Adapted from *A Little book about Person centred planning*, (Pearpoint and Forest 1998), page 129.

Keith's person centred plan graphics also contained many of these features. He had his history represented, which included where he was born, went to school, where he lived, when he moved home. What were his dreams and nightmares? What were his personal qualities expressed by others, and himself? What are his gifts and talents? Finally what does he need now, and in the future? Indeed a great deal of the circle meeting was spent resolving current problems, and planning what he would like to do with his life in the future.

The emphasis on the planning methods adopted by the circle illustrate that the first consideration is what Keith would like to do next in his life. What challenges does he need to face and overcome to achieve those aspirations. What is currently happening in his life, and how does he want to change matters? What resources are needed to assist him? This includes people and services, including members of his circle. Finally, who is going to implement the changes required, when will they occur, and who will undertake responsibility for action? None of this is written down, but the circle members all take responsibility for the actions they have agreed at the meeting. As Nigel and Charlotte describe:

C2. Nigel. "Yes it's an equal partnership with everybody where everyone can air their views, Keith can say what he feels and he's not sort of patronised at all.

C3. Charlotte oh god no and I think we all genuinely like each other. You know I am very fond of Keith but as a friend, not as I was once was a health professional and he was a patient, client, service user. I hate names like that. He is a person that's the bottom line for me, and we're thrashing it out".

C4. Nigel. “and offering what help we can for him”.

Making things happen in this way should be the prime concern for all forms of person centred planning. It must reinforce the principles of equality, self-determination, human rights, and ethical treatment in word and deed. This is a view emphasised robustly by (Dumas, La Garza et al. 2002) and (Burke 2006) who also emphasises the need to build a positive picture of the person. This must be linked with what they want in their life, and how to obtain the information and assistance to make change happen. A key principle is to ensure the promise to help them change their life is kept alive. The way Keith’s circle plans with him fully supports these principles.

EXPRESSIVE AUTHENTICITY

This form of authenticity concerns itself with being true to its nature. In this case the question arises does person centred planning support Keith and the circle members in the way that firstly Keith wishes to be supported? and secondly the way circle members wish to support Keith? In order to achieve this the circle naturally employs features of nominal authenticity. The group personalises these to the individual and contextual situations described in this study, when they become expressive authenticity.

Keith is at the centre of his circle, the group work in a manner supportive of his individual aspirations, wishes and autonomy. Many of the circle members expressed a wish to have their own circles of support, particularly in times of

difficulties. Circle members are there to support their friend Keith, but they are also there for themselves. Many look forward to the meetings, and really enjoy attending. There is a great deal of humour and fun involved, as well as the serious work of planning.

The group have developed a shared meaning in the way they support Keith. This recognises that they have shared values and attitudes. They are all also connected in some way. This further reinforces the group, and individual's common shared identities and values. They also genuinely like, value and respect each other, and the differing opinions expressed in the meeting. When a disagreement takes place it is handled in a manner supporting mutual agreement, and understanding. Often this persuades individuals to adopt a different position. All the members view Keith as a person in his own right; this is a very important distinction. Without equality within the group, and a willingness to succeed it is unlikely that any real change will take place in the person's life. All members have seen a marked difference in Keith as a person, and they report positive characteristics. This is another critical factor for success. Viewing an individual in terms of a negative reputation or an interesting case study, or an intervention that has to be completed, is unlikely to give the person the life they would like. If one accepts that the group have developed a shared meaning in the way they support Keith within the circle how has this developed? The group have known each other for many years and are all connected in some way:

C41. Charlotte. "Well we are all joined in some way you and I have worked together, you worked with Dawn, I worked with Dawn also, Keith

and Janet”.

As a result they have developed a unified approach to supporting Keith. This represents expressive authentic values and attitudes. Levinas would view this as a matter of the group being able to put themselves in Keith’s position, feeling his pain, discomfort and frustration of not being able to live a life similar to them. This process of reflecting on another’s experience of being in the world represents moral compassion or suffering for the sufferer (Levinas 2003). This leads the group to develop a joint approach to relieving that suffering. In this case by the use of shared values and attitudes, a common appreciation of the nominal characteristics of authentic person centred planning, an ability to adapt and apply these characteristics to support Keith in shared decision- making and ultimately a will to compassionately assist a person they consider a friend. This compassion and a willingness to assist the person get the life they would like is an important finding in this study. The ability of humans to reflect has been described at length by Husserl. He views conscious reflection as an important factor in developing an awareness of the phenomenological nature of human thought (Husserl 2012). He considers that conscious reflection is partly a conscious reaction to perceived experiences, in this case the circle of support working to assist Keith. This then shifts into a subjective conscious reflection or what Sartre would describe as a transcendental thought (Sartre 2004). This becomes part of memory so at a later occasion the individual can recall, I have perceived this experience, I have remembered this experience, I look forward to this experience, I will act in the following way. This is evidenced in the data when many of the circle members recall, looking forward to attending Keith’s meeting. Janet’s interview extract highlight these views:

J29. Chris. “Is there anything else you want to say before we stop?

Janet. Well it’s all very positive especially for Keith, I quite look forward to going to the meeting. It’s all good having a positive influence on Keith and his life”.

In this way a connection is made between authentic thought, within an ethical phenomenological/existential discourse. This also leads to a consideration of individuals in the circle (including Keith), reflecting on themselves, and developing a view of themselves.

A VIEW OF ONE’S SELF

Since the purpose of person centred planning is to focus on an individual. It also seems important to reflect on how individuals view themselves, as a part of the process. Also how their views develop, and evolve as a result. There were a few specific references to this contained within the data collected, but I believe those that were present add significantly to understanding such underlying meanings, and constitute the “truth” concerning the expressive authenticity of person centred planning for this group. Extracts are centred on Keith since he is the focussed person in the group. Group members also report within the data, that he has made great progress from having meetings, and developed and grown as a person. His parents, Tom and Sharon express the following views in their individual interview:

S6.Tom. “I think that brought out very well the confidence that Keith seems to have gained with the circle than he had before Sharon do you

find that? The way he talks about what goes on at (name omitted) and wherever.

Sharon. Yes.

Tom. He now tells everyone what goes on whereas before he wouldn't I t has helped bring him out of his shell to a certain degree.

Sharon. Since we had the meeting he has made it clear that he doesn't want that lady again and it's on his care plan that she shouldn't deal with him.

Tom. He says things some times to the senior staff down there and I think Keith you can't say that , and he says I know what I am entitled to, and he will actually tell people whereas he would never say anything before would he Sharon".

One of the key features for Keith is that he is in control of the meeting. He is listened to, and what he says is acted upon. This shows a great sense of self-assurance, and an ability to advocate for himself. Also he knows exactly what he is entitled to. The extract below from Keith's interview clearly illustrates this:

K1. Keith. "Well first of all I thought I was controlling the meeting well, um well obviously we were trying to sort out a problem mum had her view I had mine. I thought it was a bit of a battle there, but we managed to sort it out between us. Mum was sort of saying I couldn't have me day out and I thought, well I can if the (name omitted) want me they will have to provide transport and stuff".

This supports the views on personhood found earlier in the literature review that a key element to developing a sense of self is that an individual's views are listened to, and acted upon. The person feels a sense of belonging, and it fosters an individual's sense of belief, in effect they are a valued powerful person (Renzaglia, Karvonen et al. 2003; Dearden-Philips and Fountain 2005) . Keith is constantly trying to please others. He states numerous times that he doesn't wish to let others down, particularly his parents. This may have been a result of past experiences since he avoids any form of conflict. He also gives insight into lacking self confidence, or belief in himself, for example:

T18. Keith. "It certainly has, I mean I don't feel quite so scared about living on my own now. I always have been a bit of a loner anyway. I like my own company. Susan comes over and sees me, and it's nice that all you guys keep in touch and stuff. Thanks to mum and dad I can still keep in touch with them three times a day. (All laugh)".

However, he also recognises that he is growing in confidence, and this has been a direct result of the way the circle support him:

T21. Keith. "Yeah. I feel a lot more confident in myself again. I can actually say no, you know it's like I always tell mum and dad what I am going to do. It's like basically, they were chuffed to bits when I was going to go around with the manager, and talk about (name omitted). It's not just for elderly people living in the flats.

Dawn. When we talked about you living independently we were talking about 24 hour care. Now you get 2.5 hours a day”.

Keith also uses a number of different acronyms to describe how he is feeling. I suspect this represents some of the hidden “Truth” for him within the circle, and his life outside in the community.

For example, when describing his treatment in a particular service he talks about being the black sheep. During the interview I encouraged him to explain what that meant.

K10. Keith. “Well it means if somebody eh, if you are a family member and you go away, I’ll let Chris explain.

Chris. No you say Keith because you said it.

Keith. It means you’re the renegade of the family, and they don’t want to know you for a while, and you get shut out of things when you are supposed to be a family member”.

He clearly understands the way he is being treated, but he expresses the wish to be like a little boat:

T23. Keith. “You know about the little problem I had. I want to be like the little boat that goes between the two harbours, people know me and I do my advocacy work with a smile.

Dawn. I think it's a really good thing to speak about Keith because you use (name omitted). You use that service, you are in a better position than anybody to advocate for people who are still using it.

Keith. When I spoke to the manager last week, she was very interested in what I had to say".

This could be interpreted in a phenomenological manner as wishing to find a safe harbour protected from rough seas. Perhaps, alluding to a connection with avoiding, conflict, arguments or trouble. Actually it means that he wishes to be a mediator. This can be seen in the following extract from the circle meeting:

T22. Keith. "I went back to (name omitted) last week, and they are thinking about setting up a friends of (name omitted). So they have asked me to join that. I also suggested that they need an advocate. So they are looking into that as well, because that's the sort of thing I would like to do in future. If somebody with a disability had a problem I would find out what it is and negotiate. Be like the American secretary of State. Charlotte. What you want to be Hilary Clinton? (all laugh).

Keith. No when he was ferrying during the Falklands war, between Argentina and the British Government, and that. That's the sort of advocacy work I want to do.

Dawn. Mediation.

Keith. Yes mediation".

This may also illustrate that Keith knew in his subconscious what he wanted to say. He grasped the concept, but didn't know the word. By using subconscious reflection he was able to recall a previous perceptual representation of the American Secretary of State in the Falklands war. He clearly reiterates this process in the following statement from his individual interview.

K15. Keith. "I go through life wearing like a pair of armbands, and I use that as an armband support basically because I didn't know what to say. That's why I said we need a vote on it really.

Chris. So you meant for the group to help you but not actually say you have got to do this?

Keith. Yes that's how I see the group working basically, they give me some guidance and advice or whatever, on where I should go next".

Keith is encountering the world at two levels. Firstly, the world of the circle of support within it, he feels secure, safe and supported. Secondly, he is also aware of being a member of a wider social world. In choosing for himself he also chooses to act for other people in society (Sartre 2007). This suggests that a person with a learning disability can experience the world in the same way as anyone else, but also can experience it in an existential manner, as a result of subconscious, transcendental reflection. This is also a very important pre-requisite for expressive authenticity (Sartre 2004).

OTHER INDIVIDUAL VIEWS OF SELF

The other circle members made very few comments that could be attributed to

an awareness of their own selves. However, there are a few occasions when insight can be gained. One of the difficulties for any professional is letting go the cloak of professionalism (Pearpoint and Forest 1998). In Keith's circle there are four professionals, two of whom are retired. All make the point that they attend in their own time not representing a service, but they are still representing their profession?. Does this represent a conflict within their own views of their self? Even though they are not paid to be present, they still have a professional background. Dawn's interview extract alludes to some of the conflicting issues:

D8. Chris. "Yes but in a way that's advantageous to the way the circle works.

Dawn. Yes it is I think. I have got quite a powerful position in that I have got quite a good relationship with mum and dad, and they asked me for a lot of advice as they do you, and look to me to sort things out for them and so does Keith".

Dawn accepts she has a powerful position without really wanting it. She goes on to say:

D19. Chris. "I like what you said earlier about affirmation perhaps that's an important part of being in the circle.

Dawn. yes and for me as well if I'm being honest, because I work quite isolated as you do. It's me who is the core at work and all the guys look at me as if I'm some sort of Oracle, to be able to solve the world's problems which of course I can't. So I need the affirmation as well from

everyone in that group there is a lot of people that know Keith really well, and everybody there has his best interests at heart and is solely there for him. As well I enjoyed that aspect of it. I put things out on the table and make sure that I'm doing it right for him".

So Dawn attends the circle meeting not only to support Keith, but because she likes to have the affirmation from everyone else present. By that she means she appreciates having other members support, guiding her and all present to problem solve. Being a lone worker obviously leads to professional isolation, and she does not want to be seen as she states "the Oracle" solving everyone's problems. She does accept that she does offer her professional expertise, but it is always in a way that will help Keith. The following extract explores the issues further:

D31. Chris. "Why do you think they don't work then?"

Dawn. I think the circle doesn't work because it has the wrong people in it, people are coming for the wrong reasons. I think the thing with Keith is that all of us are professionals but none of us are there because we were paid to be there. It doesn't work when people have been told to be there because they been told to turn up. They aren't making any true commitment to that person and that's what it is all about. I have also seen a few times where if people aren't prepared to give something of themselves to the circle than it will not work. It is not just about the person giving, everybody has to give something, and when it doesn't work it is when it is not the right mix of people".

Clearly Dawn has experienced other circles where people are told they have to attend. The issue is about commitment for her, and true commitment in particular. She also reinforces the point that people attending have to be prepared to give a little of themselves. Perhaps there is a role conflict here, but Dawn does not view it as a major issue. She is attending because she wants to support her friend Keith who is also a colleague, as they work together. She is making a true commitment to him by giving something of herself. She views her professional role as enhancing because she can draw on her knowledge and expertise, when it is needed by the circle. She does not wish to be seen as the most important person, and is not precious or guarded of her professional role. In this way she is also benefiting from attending the meeting. It's pleasant, fun and she is acting freely without service constraints. Together united with likeminded people to help a person they all genuinely like, and wish to spent time with. She is also prepared to give a little of herself whilst attending the group, emphasising the sharing culture.

This fully supports the whole point of expressive authenticity “being true” to itself can take place at many levels, the individual level, the group level and finally supporting nominal authenticity through the application of the principles and foundations of person centred planning. Jane alludes to being frustrated by the administration and resource restrictions imposed at work. These prevent her from offering innovative and creative solutions, aimed at promoting personalisation. Certainly there is no conflict between the professionals, or paternalistic attitudes, indeed all of this group would be considered “normalisers”, actively promoting personalisation in all its forms (Deeley 2002). Many authors involved in person centred planning support these attitudes, but insist on rejecting professional terminology or jargon to make the point that planning should be described as

creative, almost an aesthetic experience. They describe planning as “opening their hearts and dreams”. It represents to them as individuals “surgery on the soul”, a view also supported by the data in this research (Pearpoint and Forest 1998; Hingsburger 2000).

Only by fully participating, giving of themselves freely without any other agenda can an individual really understand what authentic person centred planning means. This includes a rejection of paternalistic professional attitudes, and the use of professional words or jargon. This is a direct contrast to instrumental authenticity which will now be contextualised.

INSTRUMENTAL AUTHENTICITY

The data in Keith’s circle yielded a few examples of what could be considered Instrumental authenticity. Most of the examples concerned services and the way they engaged with Keith. Often this involves inappropriate treatment of Keith, for example manipulation or deception. Keith described numerous occasions when, he was “let down by services”. One occasion was when he was included by a service just to tick a box in an inspection. They needed to be seen employing a person with a disability on the team. In fact Keith was never paid, and was constantly being given excuses as to why he could not be provided with transport. This was one of the matters discussed at length in the circle meeting. Dawn’s conversation clarifies the position:

T4.Keith. “I just feel do I want to put myself through all that disappointment again.

Sharon. It’s up to you.

Dawn. What they want is (name omitted) to go around all the (name omitted), and do safe places because they want me to do it with you. But that is not how we work, they need to pay us and they are not prepared to do that, so they are trying to do it without paying us. They need to support your transport, support you with somebody when you are there, make sure you have got the equipment you need, and PowerPoint presentation, and that all sorted out”.

Unfortunately this appears to have been a situation experienced by other people with learning disability, particularly with the increased use of personalised budgets and care in the community .The rise of personalisation was viewed by many in the political field as the most appropriate way of providing services for people with learning disability. The reality is all too often a similar experience to that experienced by Keith. Not only does this emphasise the professional gift model where the person is the last point of contact in the decision- making process, having first to be assessed by a professional for service eligibility through the administration of rigorous, inflexible, criteria. They then have to be assessed by one or more professions to ascertain what their needs are, and what interventions are going to be provided. This is then recorded on a computer system so the “quality of the service” can be measured (Duffy 2011). It acts in opposition to the citizenship model proposed in person centred planning, and emphasised throughout this thesis. Janet describes her frustrations in the following extract:

J28. Chris. “I don’t know I have an open mind on it at the moment. You are a facilitator and use person centred practice, do you get frustrated with the system sometimes?

Janet. Oh yes I spent some time developing person centred assessments with pictures for people, only to be told we can't use them on our computer system. The people and their families really like them because they were easy to read and understand. It's also about looking at the positive side of a person not just about their behaviour. We have to do core assessments and the first question is, have you ever had a mental health problem, or ten steps forward and ten steps back".

This reinforces the findings discussed previously in this research that professionals should not be viewed in negative terms or excluded from circle meetings. System control can be equally frustrating for them as well as people trying to access services (O'Brien and O'Brien 2002).

Although the group resolved this issue by supporting Keith to go and meet with the service manager, he no longer attends this particular service.

The other occasion of Instrumental authenticity described occurred when Keith was told he did not have a learning disability, by a member of staff invited to attend his circle meeting. I would like to describe this incident in detail because it had a profound effect on Keith, who had to agree to be assessed and tested for his level of intelligence to be established. Janet described this in some detail during her interview:

J25. Janet. "He went back through an assessment process and had the right thorough assessments to prove he should be in the learning disability field.

Chris. Did you feel the circle helped with that?

Janet. Oh yes certainly for sure. Everybody supported Keith everyone did all the relevant referrals and made sure it was actioned and not forgotten. The circle is not only for Keith it brings something to other people in the circle as well. For us we don't want that experience to happen to anyone else. It's learning from experience for all of us to make sure something like that never happens again. People hook onto this I.Q. thing you have to have an I.Q. less than 70 to get to use our service. It's looking at the whole person and getting lots of different assessments. Keith had an independent assessment. It was a difficult time, but Keith has come back stronger".

Janet makes an important point about learning from experience for everyone in the group. This reinforces the shared meaning and values common to the group members. These are then galvanised into agreed actions, with the emphasis on supporting Keith. This is achieved within the framework of developing personhood expressed within the features contained in the conceptual model. At differing times in his life different features will come to the fore. In this case the emphasis was on positive choice, inclusion and control. Keith was seen by an independent organisation (supported by circle members). The very fact that he had to agree to be tested in order to access a service could be viewed as a breach of his human rights. He was again not being viewed as a person, but as a referral. Process overtook treating him as a human being. Keith described the experience as follows.;

K26. Keith. "I guess because I had the right support, and people knew where to go, and I knew that I had to fight to clear my name in some

respects

Chris. Clear your name can you say what that means?

Keith. Yeah it means that I had been in the same service for as long as I could remember, and I felt the person was making me a pariah and wiping his hands clean of me and my problems by fobbing me off to somebody else. I think when I met the person from the (name omitted) service she realised I had a learning disability.

Chris. So how did they find out you had a learning disability?

Keith. I went to (name omitted), and did a few tests, and they discovered I had an I.Q of 69 so I just made the cut off point”.

For Keith he was determined to clear his name but the experience made him feel very unsettled. He was in danger of losing all his friends, colleagues, social and community links. As a result of the assessment process and testing, he just managed to remain within a service he had been part of all his life. Dawn commented that Keith was very much a product of the services he had used. This was not meant in a derogatory manner, simply it emphasises the need that people using segregated services within” learning disability service land” often become devalued institutionalised and loose, the skills necessary to live an inclusive life in the community. They also become viewed as “other” by the community at large. It is possible that this can become internalised with the self concept of the individual the (I) in Meads view of human interaction. We present a view of ourselves (Me) directly as a result of our interaction with others. It is quite possible that Keith’s (Me) is a direct result of having spent a considerable time in institutionalised services, and in addition, his own view of himself could be that of “other” (Blumer 1966). Different from

the rest of society. He relates this to being a “pariah”, or the “black sheep”. Someone who is an outcast, a renegade “people don’t want to know you for a while, you get shut out”. Clearly previous experiences have affected Keith to think of himself in this way. Goffman (1990) explores this view in some detail, when we present ourselves to others we do so in the situations and contexts we find ourselves. This affects how we relate to others; we play different roles depending on our audience. If individuals are defined in negative roles then they learn to accept that role. In Sartre’s view (2006), if a person is responsible for defining their own life then it is not surprising that Keith defines himself as different because of these experiences.

It may also lead to an explanation of why citizenship was not prominent in the developing conceptual model. This can be illustrated in Keith’s response to self directed support. He has chosen a direct payment, but it is administered through the Local Authority. His circle constantly encourages him to embrace citizenship, but he finds it difficult. Currently he is exploring how to become an assertive self advocate. His parents and other circle members have noticed he has changed and is more confident and speaking up for himself. There was also a mention of him viewing himself as “sometimes not liking himself ” in the visual data (**Appendix 5** under worries and gifts), which further reinforces his feeling of low self worth.

Personalisation should start with the individual not the service. There is a very marked imbalance in power here. In order to access services people have to agree to be tested and assessed. A variety of differing criteria are used to define service eligibility. For example, in order to access Community Care services an individual is defined as a vulnerable adult:

“ a person who is or may be in need of community care services by

reason or mental or other disability, age or illness, and who is or maybe unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation”.

Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse,(Department of Health and Home office 2000), Pages 8-9.

This description defines a person in terms of impairments, in need of protection and reinforces a medicalised disempowering model. Not all people with learning disabilities should be viewed as in need of protection, but this approach has happened as a direct result of two factors. The first is that recent government policy has tended to promote services that are effectively delivered in a cost- effective and efficient manner (Dept of Health 2010). Unfortunately cost- efficiency savings often lead to lack of resources both in terms of skilled people with appropriate knowledge and expertise, and the lack of resources in terms of materials, equipment and time. The result leads to the second factor, an increasing number of abuse investigations, and not just in learning disability services (HM Government 2013).

However, for Keith at the moment when he was told he did not have a learning disability his whole world was turned upside down. His mother and father described this moment succinctly “it broke his heart”. This is hardly surprising when one examines his relationships. His relationship table on page 137 illustrates this very well. The majority of his friends and relationships are either with people who have a learning disability or those who currently work within those services, or who have worked in these services in the past. He was in danger of losing all his friends

and relationships. Also his voluntary job, his hobbies and activities all revolved around people with learning disabilities, and learning disability services. He described having to clear his name, and viewed himself as a pariah, a black sheep. Keith expanded on this explanation when I encouraged him to explain during his interview.

K10. “No you say Keith because you said it. Keith. It means you’re the renegade of the family, and they don’t want to know you for a while, and you get shut out of things when you are supposed to be a family member”.

It is possible that Keith was referring to an incident in his past when describing these terms. Clearly he has experienced being shut out of things, when he was supposed to be included. Without the support of his circle the consequences could have been severe for his individual sense of identity. However, he was supported over a period of months, to be independently assessed by his circle members. They also continued to visit him and encourage participation in activities he enjoyed. They were also available to council and support him, and as a result a number of circle members stated he became stronger and more assertive.

It is possible that his reluctance to move out of learning disability services is a direct result of this incident. He feels safe and secure in these services and currently identifies very strongly with them. There are similarities with the position of Deborah as described by Goddard (Smith 2006). She identified so strongly with being diagnosed as mentally retarded that she could not conceive living her life outside an institution. Although it would have been possible for her to live an “ordinary” life given the appropriate support. Deborah viewed the outside world of the community as a

dangerous place. I don't believe that Keith views the outside world as dangerous but he certainly prefers to use learning disability services. This was not always the case his mother Sharon states that until the meeting he didn't want to be labelled with a learning disability. He wanted to be like his brothers, and everyone else. So it is possible that Keith's view of himself was changed by the incident, and as a result he identifies strongly with having a learning disability. However, his circle still encourage him to mix with people living in the community outside of learning disability services as Sharon commented in her interview:

S19. Sharon. "I think because of the circle he felt able to talk to people outside of his home environment. It's been a big thing for him. Its helped him judge what are the right kinds of people to mix with".

Clearly in the past Keith has been involved with individuals who have abused his trust, he is now learning to avoid those individuals and situations but remains committed to remaining within learning disability services.

This incident and its effects on Keith illustrate the importance on establishing the core principles of any service, policy or procedure. These should be based on the understanding that human beings have a right to be treated equally, with dignity and care (Department of Health 2009). Only by truly valuing a person irrespective of context can an authentic person centred approach be taken.

The final part of this thesis includes a description of the contributions of this study including suggestions for future research, and a number of recommendations and concluding remarks.

CHAPTER 4. CONCLUSION.

INTRODUCTION

This is the concluding chapter of this study. It includes a discussion of the contributions the study makes, including professional and theoretical contributions, and outlines the study strengths and limitations. A number of recommendations are made regarding areas of future research, and the chapter concludes with a summary of the study, and importantly a concluding statement from Keith.

STRENGTHS AND LIMITATIONS OF THIS STUDY

Whenever research is conducted it is important to recognise that it is never undirected, it also never stands on its own (Mayan 2009). Research must engage with a variety of different agendas be they political, philosophical, ontological, or indeed those grounded within a given subject area or field, as in this case (Pillow 2003.). Being a reflective researcher requires not only an appreciation of what your particular study contributes to the field, but also what limitations were found, or could be considered by others. It must be appreciated that qualitative research is not viewed by all within the research community as a rigorous research method. It is often considered unscientific, based as it is on interpretations, of naturally occurring humanistic phenomena (Griffiths 1996). I hope the way the data has been collected and analysed in this study has refuted some of these empirical concerns.

As a researcher I was known to this particular circle of support before they agreed to participate, that could be viewed as research bias. However, since the

study is in part ethnographic, and by its very nature that means the researcher needs to embed oneself within a particular culture, in this case Keith's circle of support (Edwards and Belanger 2008). I consider this to be appropriate, and indeed beneficial to the research process. This was particularly evident during the interview phases. Individuals were at ease with what was essentially an emotional conversation with the researcher, about their experiences (Rolph and Atkinson 2010).

However, I was aware that when attending the circle meeting I was present in a different guise, that of Chris the researcher. There were occasions during the conversation when I felt I should contribute since this is what I would usually do when attending a meeting. However, everyone present appeared to accept that I was there in a different role, and it did not appear to affect individual's contributions with the exception of Susan. Individuals engaged in conversation as they usually did and the meeting took its usual format of actively supporting Keith in a comfortable and friendly environment. Perhaps I was constructing a different (Me), and because of previous social interactions with this group it enabled them to accept "Chris the researcher" in this new role. Also it enabled, "Chris the researcher" to accept my own redefined self concept. An important point with regard to existentialism is that individuals constantly redefine themselves, and although I was unaware of this consciously taking place, perhaps it also contributed to my acceptance in this group, who may also have experienced this phenomenon (Nye 1977, Sartre 2004).

It has to be appreciated that this is a small- scale study, and it was conducted with a person who was very capable of making his own views known. Many people with learning disabilities are unable to communicate verbally or need total

communication strategies. For example, the use of photos, specific signs or symbols, or computer- assisted technology to enable full participation (Wright 2005; Poncelas and Murphy 2007). However, there is no reason why without personalised additional assistance such individuals would not be able to benefit from the contributions to practice highlighted in this study. Although the methods used for data collection would need to be revised to meet specific individual needs.

THE THEORETICAL PROFESSIONAL AND METHODOLOGICAL CONTRIBUTIONS OF THIS STUDY

Person centred planning is no longer in its infancy , but research in this field has tended to be quantitative in nature (Robertson, Emerson et al. 2005; Emerson and Hatton 2008). By utilising, an essentially humanistic theoretical foundation. Incorporating a phenomenological/existential approach based on philosophical thinking around discourses arising within the study that relate to human existence, and how individuals experience the world, a new approach has been taken, particularly in relation to people with learning disabilities

This study has developed a new way of considering the authenticity of person centred planning for people with a learning disability using services in the UK. These considerations are equally applicable wherever people with learning disabilities are located and were described as authentic attributes in the conceptual model developed as a result of this study. There is an emphasis on the need for people to be at the centre of all decisions related to their life. They should also be able to exert control over these decisions, and be supported by people who treat them as valued individuals. It needs to be acknowledged that they can make significant decisions related to who they want in their lives, where they wish to live, and how they are

going to be supported, to achieve the life they wish. It may be argued that these attributes are not new but this study has emphasised their inclusion as a precursor to authentic person centred planning.

This study suggests that people with learning disabilities are able to consider their place in society, and possibly at a phenomenological level. They are also quite able to develop their own self concepts, perhaps thinking philosophically, in this particular case existentially. They can consider their place in the lived world generally, and also their place in the " world of the circle of support". Although it is likely that their level of learning disability, may affect the degree to which this can occur. In Keith's case his learning disability and associated difficulties, mean that he has difficulty sometimes with regard to receptive communication. He also admits to failing to understand complex sentences, particularly when individuals use professional terminology. Often he fails to process the information, or comes to the wrong conclusions. He has a very good use of expressive language, but often uses words and sentences without really understanding their meaning. Keith's use of expressive language has resulted in some individuals questioning his use of learning disability services. This was particularly highlighted in the incident described in this thesis, where he was told he did not have a learning disability. Following assessment by an independent organisation Keith's intellectual functioning was found to be within the range required for an individual to use learning disability services e.g. less than 70 (Department of Health 2001). In addition he also meets the service criteria for a vulnerable adult in receipt of community care, and as a result has continued to be supported by a number of learning disability professionals (Department of Health and Home Office 2000). He is currently receiving a direct payment which is administered for him by the Local Authority. This enables him to purchase services

from other providers (H M Government 2007). Currently these are entirely related to people with learning disabilities, since Keith is very reluctant (since the incident) to use mainstream services. Clearly his concepts of self worth and identity have been very severely affected. I explore these issues in greater detail within the section devoted to this incident (please see pgs 212-218)

His circle attempt to overcome these difficulties. They work as a circle of practice, which is essentially a social space of like-minded individuals. They work together to maintain this space with a common shared aim, in this case supporting Keith. Within the space individuals operate at an individual level to maintain their own position within the group, but also and as a cohesive community. The study indicated that this circle share common aims, goals and values, but they also have individual reasons for being a group member. Some concern individual aspirations, for example, a wish to enable Keith to get the support he needs to live an “ordinary” life integrated within his local community, but also a wish to have their own group who can come together, and help sort out the problems of everyday life (Fairclough 1993). This application could be extended and generalised to support other groups of people, for example older people, people with dementia or other mental ill- health, and people receiving community care when discharged following an episode of acute care in hospital settings.

The principle themes reported in this study emphasise treating people with dignity and respect, enabling and encouraging self advocacy, and the utilisation of professional skills and expertise when required. However, always in a manner that respects the individual and values their gifts, hope and dreams. It also suggests the utilisation of compassion and empathy.

This study emphasises the importance of gifts, hopes and dreams as an integral part of authentic person centred planning. They are an integral attribute within the conceptual model, assisting the individual define their own concept of self and their place in society because of the linkage with control (Hopes and dreams were a sub theme to control in the conceptual model), and personal qualities (gifts were a sub theme to personal qualities). These relationships are illustrated in **Appendix 8**. If an individual has control over their life including their dreams and aspirations a sense of hopefulness develops. This is further reinforced if they also feel their personal qualities are valued by others through giftedness.

Individuals have great difficulty accepting the concept of giftedness assuming it applies in an esoteric way. Gifts are essentially capacities to interact with others and create opportunities (Pearpoint, Forest et al. 1993; Snow 1993). They are more than a prescribed intervention, a treatment plan or assessment. They are what attracts individuals to support a person, join a group or develop a hobby, and give something of themselves for mutual benefit and enjoyment. They were one of the sub- themes related to personal qualities in this study, and that describes them very well. They are closely linked with interests, knowledge and shared values. Likewise hopes and dreams are often assumed to be irrelevant, but this study has indicated the opposite. Although they were not as prominent as initially anticipated .This was because at this particular time in Keith's life, hopes and dreams were not the major issue discussed by his circle of support at the circle. Also it is possible that currently Keith's view of himself does not include the Sartrean concept of being-in-the-world. He is being-in-the-world for others, and also being-for-itself. Sartre considered this

rather akin to being in the midst of the world. It represents an existence, but does not include the individual developing all his potentiality and capabilities, to become what he/she is capable of becoming. He suggests it represents a life, but not really leaving life to the full (Sartre 2008). Although hopes and dreams did appear in Keith's person centred plan graphics, and their relevance was indicated in later interviews. They give people a purpose, a future goal and a sense of hopefulness. They are linked very closely with being in control of your life, and clearly are an important component of decision making, promoting self advocacy and power over individual destiny.

There is also the ability to assist others in achieving their own goals through acting within an ethically driven framework, of shared values and positive support. This in turn promotes inclusion through resource knowledge and community knowledge resulting in community presence. In this study the individuals had a wide knowledge of local and national resources. This was common across the individual group members although some (typically Keith and his parents), expressed the opinion that they did not possess as extensive a knowledge as the professional members. A view not supported by other members who consistently in interviews stressed the importance of the contributions of family members. Indeed this is a view supported by a number of authors who consider such contributions as essential and offering new insights and directions to enable effective joint working with people with learning disabilities (Department of Health 2001; The Learning Difficulties Research Team 2006). It was also interesting that all the professionals in the group attended in their own time, and in these days of budgets, costing and finance there was a nil cost attached to any agency for Keith's group to meet (Duffy 2011).

The group have also introduced a process of guided decision- making which

enables the person they are supporting to become an active self-advocate. This in itself has resulted in a considerable personal development of both Keith and his girlfriend Susan. Susan needed some additional one-to-one support and guidance, to enable this process. This supports the process of guided decision-making the group in this study utilise, and is in direct contrast to substitute decision-making. Often staff act in the person's best interests without carefully considering the person's needs (Dunn, Clare et al. 2010). In Susan's case this involved simple, clear explanations, and easy to read and understand literature. When this was provided she was able to make her own decisions, and act in her own best interests, for example she is now developing her own circle of support. This study has illustrated that person-centred planning is complex. Individuals often require additional support which goes further than providing graphics, or alternative easy to read literature. This has been supported by the metaphysical approach which has emphasised the importance of individual imagination, feelings, and thoughts shaping individual experience to make sense of living in the world.

This study has also considered and developed the basic foundations of supporting people with learning disabilities in circles of support. The conceptual model developed from the research findings highlights the key attributes required. These were produced in the form of themes and sub-themes, and the qualities needed for those participating. The need to enable, encourage, plan with hope, support individuals dreams and ambitions through positive shared action planning and decision-making. To encourage citizen and self-advocacy, foster inclusion, develop relationships, provide positive support, and develop personal qualities. These can also be utilised for supporting people with learning disabilities to enable

social integration, social and political emancipation, and ensure people are treated ethically with care, dignity and respect. It also recognises that people with learning disabilities are able to experience life as any other citizen (Stainton 2005). When supported authentically individuals can make a positive contribution to the cultural field in which they are participating. This in turn supports and encourages engagement with the wider community. What appears to be required is a fundamental shift in policy making from a service dependant model to a service choice model, with an individual's person centred plan as being the starting point for any decisions relating to that person's life. (Smull and Lakin 2002). It is interesting to note the tensions experienced by Keith's group, on the one hand they wish to support Keith to have the life he wants, but there arises tension when they have to approach statutory services because systems, policies and procedures get in the way of promoting individualised life choices. The priority becomes the core assessment, eligibility criteria, and risk assessments. It also affects the individual and how they view themselves. Keith sees himself as a pariah, a black sheep, having to fight to clear his name. He should be seeing himself as a valued human being, with a variety of gifts to share with his immediate family and friends . I would suggest that the examples of Instrumental authenticity cited in this study represent inauthentic forms of planning and treatment.

A change in political rhetoric is required to redress the balance and providing person centred care, support and planning in a person centred way could assist, as highlighted in this study. It is not sufficient to issue policies encouraging locally based, high quality services if there is not the willingness or the staff to promote a person centred model based on egalitarian and ethical principles. The principles

highlighted in this research include basic human rights, freedom of choice, shared decision- making, recognising the person has a right to be involved in all decisions related to how they live their life including promoting a sense of hopefulness regarding their future .

It also has to be acknowledged that there is a duty of care but this needs to be balanced with the need to involve the individual and/or people who know them best at every stage of planning and service provision (Department of Health 2012). When this fails to happen the results are often harmful practice, abuse, and institutionalised approaches to care and support. However, in the 21st century it is difficult to envisage how anyone can be left within a hospital ward to starve to death (Local Government Ombudsman 2009). Perhaps a possible solution is to ensure person centred planning and care planning are linked. Encouraging the sharing of information across the boundaries of social care and person centred support (Cambridge, Carpenter et al. 2005).

AREAS FOR FUTURE RESEARCH

Further research is required in the field of individual's hopes and dreams and the possible effect it has in furthering their life aspirations. Since this is often cited in person centred planning literature as part of authentic person centred planning (Pearpoint, Forest et al. 1993; Snow 1993; O'Brien and Pearpoint 2004). This was very briefly highlighted in this research, but was not as prominent as anticipated. Indeed the hopes and dream theme was demoted to a secondary sub- theme during data analysis. The literature section of this study reinforced the importance of hopes, dreaming for a future, promoting a sense of individual identity, power and control over your own destiny. This has been supported by the findings in this study with

particular reference to ethical treatment and practice, compassionate care and support, and encouraging a sense of self-worth, civil and moral equity and an inclusive community that values diversity. Hopes and dreams are linked by some person-centred planners with the concept of gifts. This represents the uniqueness of the individual, an essential human trait. It also represents for Snow (1993) an intimate link with community. Individuals come together to create opportunities for themselves and others. They interact together in activities that are meaningful, and valued within their local community. Unfortunately there is little current research available in this area, but it does correlate with the philosophical positions taken both within this research, and current UK policy related to promoting social inclusion and dignity in care (Department of Health 2009). However, although suggestions have been made in this study as to why there were not a prominent, further research-based evidence is required.

It would also be beneficial to conduct similar research with a person who has challenges with communicating. For example a person who is part of the autistic spectrum (Frith 1993). This would hopefully yield further insights into what specific needs these individuals have in making their needs known. Also how best they could be supported to fully participate in person-centred planning. This would also endorse current aspirational policy documents that seek to improve services for these individuals, through a focus on individual involvement and promoting an inclusive society (Department of Health 2010). These are major factors in implementing authentic person-centred planning.

Further research may also be required to identify the role of professionals

participating in circles of support. Although some findings in this study indicated that professional involvement was beneficial. There was little evidence of professional conflict with regard to participation, in what is essentially an informal group. There are also questions regarding professional accountability which were not reflected in this study. Most professions require regular appraisals and formal training indeed many have to produce a personal professional portfolio. How this is managed within such an informal arrangement remains problematic. There is also a need to examine professional boundaries and their impact for individuals participating within informal care settings. Given the increased personalisation agenda this is likely to have greater significance, particularly with regard to how professionals are defined (Parkes and Jukes 2008). There remain confusing issues for people with learning disabilities, particularly regarding the designation of paid professionals, and other support staff. These often become viewed as friends by the person they are supporting, leading to issues of over-attachment, dependency, role confusion and abuse (Parkes and Jukes 2008). There is a need for further research in this area examining the experiences of both parties.

The conceptual model of attributes could also be further developed as an aid to practice in person centred planning. Perhaps it could be developed into a guide or book which would result in a practical application arising from this study. It could also be used with other people receiving care from others ensuring a person centred approach is given at all times.

CONCLUDING COMMENTS

This research has illustrated that what appears initially to be a very simple matter of implementing person centred planning, is in fact highly complex. It is

grounded within a complex ontological framework, that promotes not only valuing a person, but positively assisting that person grow, develop, and achieve their life aspirations.

It also highlights the importance of developing common values, practices, and attitudes. Utilising and developing these to foster a genuine commitment to a person, and also a community of people with learning disabilities. Many of these individuals still live socially isolated lives, subject to abuse, exploitation, the professional gift model of specialist provision, and extreme lack of control over their daily lives. When their views are listened to and acted upon, people flourish, and achieve many of their dreams, wishes and aspirations. When treated with care, dignity and respect, people foster a positive self- image. This benefits both themselves, and the communities in which they live. They become persons capable of helping others, thinking in creative ways. They positively enhance their own lives, and those of others who they meet. Their “gifts” enable social integration, and a sense of community is embraced. This in turn leads to enhanced community development. Their contributions become valued and encouraged at an individual and group level.

This study has answered the research question how authentic is person centred planning for people using learning disability services? The answer is yes when considered as a model of support and care both in terms of nominal, expressive and instrumental authenticity. Although by its very nature instrumental authenticity can often be linked with inauthentic ways of supporting people.

This study has highlighted how authentic person centred planning is achieved, and what individual circle members experience when they come together to plan.

The truth and essence of this experience has been situated within an existential/ phenomenological explanation of how people experience their world. Existential phenomenology supports an interest in the understanding of being. In particular it is concerned with the whole person's existence, and not just conscious interactions and thoughts. It is concerned with the whole person, how they act, think, behave and feel consciously and unconsciously (Osborne 1990). At an individual level and in particular with regard to Keith this study answers the question of authenticity partially. If it is considered that authenticity in terms of personal development requires the individual to actively seek opportunities and experience to enable them to grow as a person then clearly this is not the case. It must be stressed that Keith has many qualities and gifts, but he is yet to achieve his full potential as a human being. However, with the help of this circle it is highly likely that this is achievable.

Person centred planning is not something that is done to someone, it is not an audit tool, lifestyle approach or service development model. It is not time limited or organisational driven. Planning should be undertaken with real commitment and care for the individual person, and is a joint endeavour. It promotes a variety of interrelated concepts and factors highlighted within the conceptual model, but most importantly it encourages personal growth and advocacy. It also promotes a valued belief in individual capacities and achievements.

It is clear that the UK Government has made an attempt to promote these principles with the publication of a number of policy documents, highlighted throughout this study. Whether it is political rhetoric, or a reaction to abuse and scandalous inhuman treatment, as opposed to a genuine interest and commitment

only time will tell. This research will hopefully lead to new and inclusive ways of working with people with learning disabilities and other individuals who are socially excluded and subject to discrimination and abuse. Person centred planning can be utilised in a variety of different applications, but always supports, directs and encourages the voice of the individual.

This is supported by Keith who remains a very positive advocate for person centred planning. For him the key is to have the right people around him, people who know him and genuinely care about him. People who want him to have a life like others in society. It is only fair that in a study promoting the centrality of the individual that Keith's voice is heard:

“I will admit I have always been cynical of circle meetings, and having people there, but I wouldn't be without my circle they really do a good job. I guess it's because I have the right sort of people around me, who think the same way I do. Well they know me, and what I want basically. I like people to be quite cheerful, and you are all quite cheerful people. You listen to what I say and you don't nag me to death, which is why I chose you really. You all seem to talk a lot of sense”.

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Appendix 1. Keith's Biography

"Hi my name is Keith, I was born in Surrey and I'm 52 yrs old. I have had a learning disability all my life I also have physical disabilities which limit my mobility.

After attending a number of special schools I moved down to the west country after being bullied at the last of my schools. I attended one ESN school in the West Country and stayed there until I was 16. I realised when i was 14 that they had run out of things to educate me on. I finished school at 16 and stayed at home until I was 20.

I attended a SCOPE centre daily and realised it wasn't the right place for me. Looking on the positive side I did become the first disabled scout in this part of the West County. I also went on a sail training ship in 1989, and past my amateur radio exam. I went to a craft circle/day centre for seven and a half years. It was good at the start but then fell flat because they were concentrating on teaching people to read and write and I could already do this.

In 2008 I met Dawn and she handed me a leaflet telling me about setting up a new service where people with learning disabilities were trained to deliver training to professionals, about the needs of people with learning disabilities. I was disability advocate for the local fire services for two and a half years. This meant I had to train seven watches in the area on the needs of people with disabilities. I had to do home fire safety checks drawing up escape plans for the elderly and disabled people.

Five years ago I moved into my own flat and a whole set of new challenges arose. The major one being I was told I didn't have a learning disability by Adult Social Care. My circle of support helped me get through this, and we contacted an independent organisation who assessed me and proved Adult Social Care wrong.

In 2014 my mum sadly died unexpectedly, this was a very traumatic time but I got through it with the support of family and friends. I feel she would be so proud of what I have achieved in the last year or so. Currently I go out twice a week, I have my own radio show on a community radio station. I do my own shopping with support and attend a weekly pub quiz night with my girlfriend and other friends with my support worker.

I don't know what the future holds but I'm feeling more confident than I have for a long time. I would like to travel a bit more and also get a job at a bigger radio station, but I think my life is going in the right direction.

I didn't really know a lot about person centred planning, I met Chris at a training event all about PATH and circles of support which I knew nothing about.

I think it is a good thing as I can say who I want at my meeting and how many people should come. You come together and look at what your dreams are, different options and ways of doing things, how I want to live my life and what I want to do. We always look at good things, but occasionally I have had to look at my nightmare and that is quite scary but with the right support you can get through it.

I love travelling and meeting people from different parts of the world. One of my dreams was to present at a major international conference. I never thought that would happen considering I was stuck in a day centre for seven and a half years. If you said to me back then I would be going abroad I would not have believed you.


I didn't believe it when I was first told I thought it was a wind up. I have been promised things in the past and they have not happened. Then Chris rang dad to say he was coming round to see us, I was a bit wary and I thought he was coming to say sorry I can't get the funding. Then everything was put in place and we went to book the holiday . I thought it would take five minutes and two and a half hours later we walked out, we had to get the right facilities for me in the hotel, make sure I had enough leg room on the aircraft and I had assistance at all airports.


A week after my birthday we set off for the biggest birthday present I ever had! We stayed in a hotel in West Drayton close to Heathrow Airport. I was shocked at the price of my dinner!!! We both went into our rooms to get some sleep. Next morning Chris got me up at an ungodly hour 5.30AM to catch our flight from Heathrow. We loaded our cases and set off. I have to say that the flight from London to Los Angeles was the best ever flight; we had a new Boeing 777 aircraft. We got very friendly with one of the airhostesses who were very nice. The exciting thing was when we took off. When we arrived in Hawaii to us it felt like midnight UK time, and we had been travelling for 16 hours and flown through two different time zones. We arrived at 8pm Hawaiian time and we were picked up in a limo and given flower leis and taken to the hotel, and went straight to bed.

The best bits were the conference, speaking on the round table presentation, doing the fashion show, meeting lots of people with disabilities from other countries and seeing how their services compared with ours. Going to Pearl harbour was very emotional and another of my dreams. I love modern history. People were very warm, friendly and helpful. It made me more confident and opened a lot more doors for me


when I got back home. I now have a voluntary job as an advocate. I have met the Minister for Care Services, and taken part in staff interviews for many different services. This is an experience I will always treasure and I can't wait to go back another year."

Appendix 2. Information sheet.

Cornwall Partnership 
NHS Foundation Trust





Person Centred
Planning Research




**Workforce and Training
Learning Disabilities**
Chy Govenek
Threemilestone Industrial Estate
Threemilestone
Truro TR4 9LD


Tel: 01872 358714
Fax: 01872 358740
Email:
Chris.millard@cft.comwall.nhs.uk




INFORMATION SHEET




Hello, my name is Chris Millard and I am the researcher for this project.



I am a learning disability nurse who has worked in Cornwall for the NHS since 1989. I work for Cornwall Foundation Trust, as a trainer in learning disabilities.





The research will involve people and their circle of support working with me.

I want to see if person centred planning really makes a difference to people's lives.



You and all circle members have to say yes to take part (give consent). You will sign forms to say yes to this. I will also sign the forms.

You will be given a copy to keep.



We will video a circle meeting. I will show you a 20 minute bit of the video.

I will ask you questions about person centred planning, and what is happening in the video.



We will work together as a team to see if person centred planning works for you.

We will look at photos, drawings and other material made by your circle. I will analyse this information and discuss my findings with the group.

We will write a report together.

We will decide how the final research looks, what goes in it and who we show it to.

We will look at group rules when we first meet. If you already have some of these for your circle meetings we will use those.



It is ok for you to say no, or change your mind at any time.

If you say no we will not use any of the information you have given us.



Any information you give me will be confidential. No information will be shared unless you agree, or if you tell me something that I must pass on, to help keep you or someone else safe.



If there is a problem, or you get upset you should tell me first. I will try and help put things right. I will get the right person to help you.



At our first circle meeting members will be asked to say yes to take part in the research.

They all need to say yes before we can start.



You can phone or E-mail me any questions you may have.

Chris.millard@cpft.comwell.nhs.uk


01872 358714





Thank you



Chris Millard

Appendix 3. Consent forms



Cornwall Partnership 
 NHS Trust


Consent Form
Saying yes to taking part in research.





Name Date:





I say yes to be involved in the research.




Cornwall Partnership 
NHS Trust

I say it is ok for my words to be used by Cornwall Partnership Trust.
 Cornwall Partnership Trust has told me my words will be used for research.
 The researcher will look closely at my words and what is being said.



Chris Millard (the researcher) will write a report and talk about it with me, and my circle of support.

It is ok to say no or change my mind at any time.




Signed by Participant: Signed by researcher:

Date: Date:

If you have any questions please write to

Cornwall Partnership NHS Trust
 Chy Govenek
 Threemilestone Industrial Estate
 Truro
 Cornwall
 TR4 9LD







Or ring Chris on
01872 358734

One copy of this form for the participant One copy for researcher



C. Millard 17th December 2010 Version 3 ref10/H0107/53

Consent Form
Saying yes to my photo's being used for research.


 


Name Date:.....

I say it is ok for my photo's to be used.

 **Cornwall Partnership **NHS****
NHS Trust

I say it is ok for my photo's to be used by Cornwall Partnership Trust.
Cornwall Partnership Trust has told me the photo's will be used for research.
The researcher will look closely at the photo' and what is being said.

 Chris Millard (the researcher) will write a report and talk about it with me, and my circle of support.

It is ok to say no or change my mind at any time.

 Signed by participant:..... Signed by researcher:.....
Date:..... Date:.....
If you have any question please write to

Cornwall Partnership NHS Trust
Chy Govenek
Threemilestone Industrial Estate
Truro
Cornwall
TR4 9LD

 Or ring Chris on 01872 358734

One copy of this form for the participant One copy for researcher



Consent Form

Saying yes to being recorded by video camera and it being used for research.



Name



Date



I say it is ok to be recorded by video camera.



Cornwall Partnership **NHS**
NHS Trust

I say it is ok for the video to be used by Cornwall Partnership Trust.
Cornwall Partnership Trust has told me the video will be used for research.
The researcher will look closely at the video and what is being said.



Chris Millard (the researcher) will write a report and talk about it with me, and my circle of support.

It is ok to say no or change my mind at any time.



Signed by participant:.....
Date.....

Signed by researcher:.....
Date.....

If you have any questions please write to

Cornwall Partnership NHS Trust
Chy Govenek
Threemilestone Industrial Estate
Truro
Cornwall
TR4 9LD



Or ring Chris on
01872 358734

One copy of this form for the participant

One copy for researcher

GRADUATE SCHOOL OF EDUCATION

CONSENT FORM

I have been fully informed about the aims and purposes of the project.

I understand that:

there is no compulsion for me to participate in this research project and, if I do choose to participate, I may at any stage withdraw my participation

I have the right to refuse permission for the publication of any information about me

any information which I give will be used solely for the purposes of this research project, which may include publications

If applicable, the information, which I give, may be shared between any of the other researcher(s) participating in this project in an anonymised form

all information I give will be treated as confidential

the researcher(s) will make every effort to preserve my anonymity

.....
(Signature of participant)

.....
(Date)

.....
(Printed name of participant)

.....
(Signature of researcher)

.....
(Date)

.....
(Printed name of researcher)

One copy of this form will be kept by the participant; a second copy will be kept by the researcher(s)

Contact phone number of researcher(s):

If you have any concerns about the project that you would like to discuss, please contact:

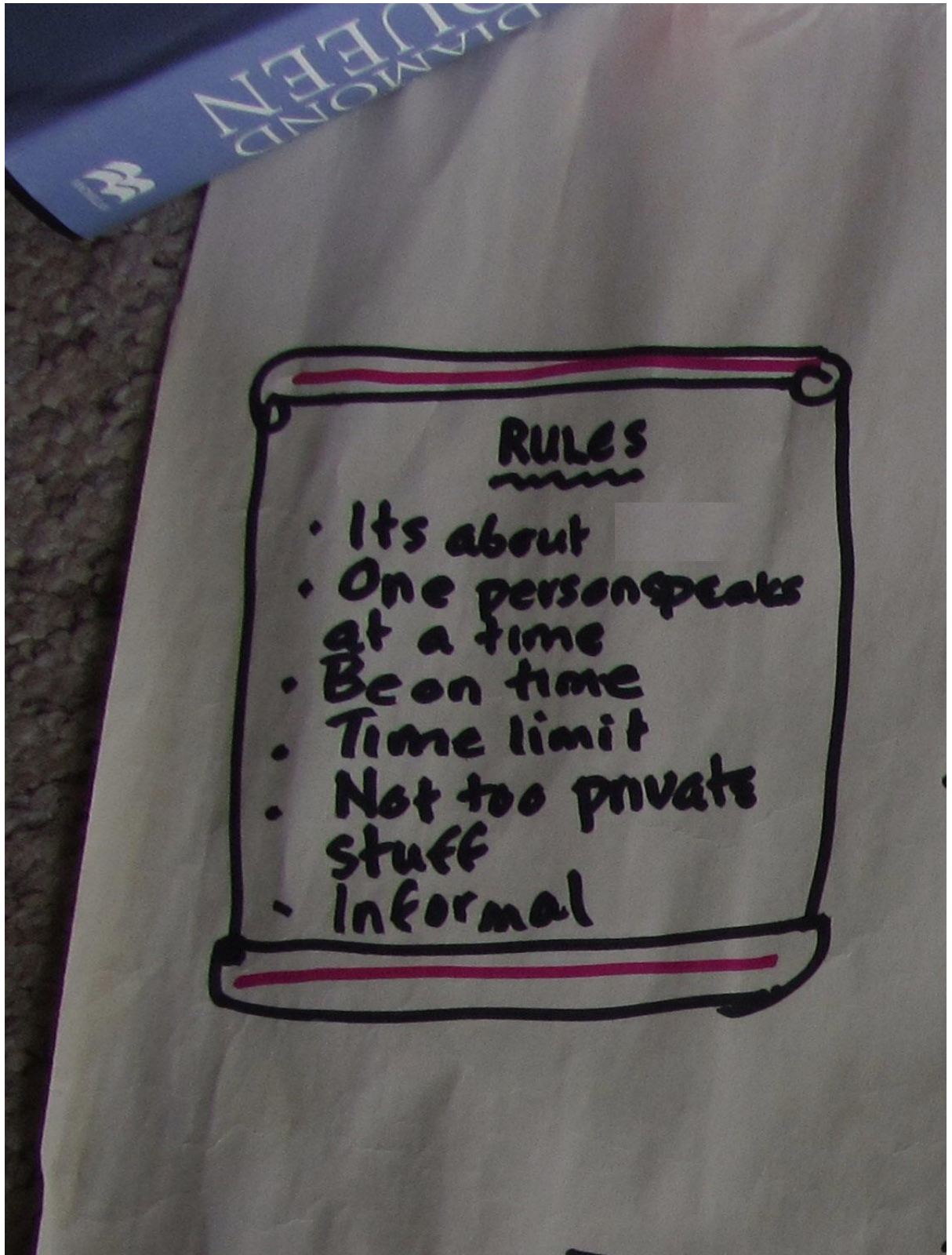
.....
OR
.....

Data Protection Act: The University of Exeter is a data collector and is registered with the Office of the Data Protection Commissioner as required to do under the Data Protection Act 1998. The information you provide will be used for research purposes and will be processed in accordance with the University's registration and current data protection legislation. Data will be confidential to the researcher(s) and will not be disclosed to any unauthorised third parties without further agreement by the participant. Reports based on the data will be in anonymised form.

CJM 17th December 2010 Version 3 Ref:10/H0107/53

Appendix 4 Rules for meetings.

Keith's Rules.

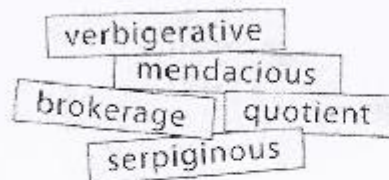


Rules for Meetings

Take care about the way we speak and the language we use.



Do not use jargon(made up names), complicated words(longwords), and technical terms(special names).



Stick to what we are there to talk about.



Work together, and work as a friendly team.



No Swearing or being hurtful



C.Millard 12th July 2010 Version 1 ref10/H0107/53

No Fighting



No Rudeness

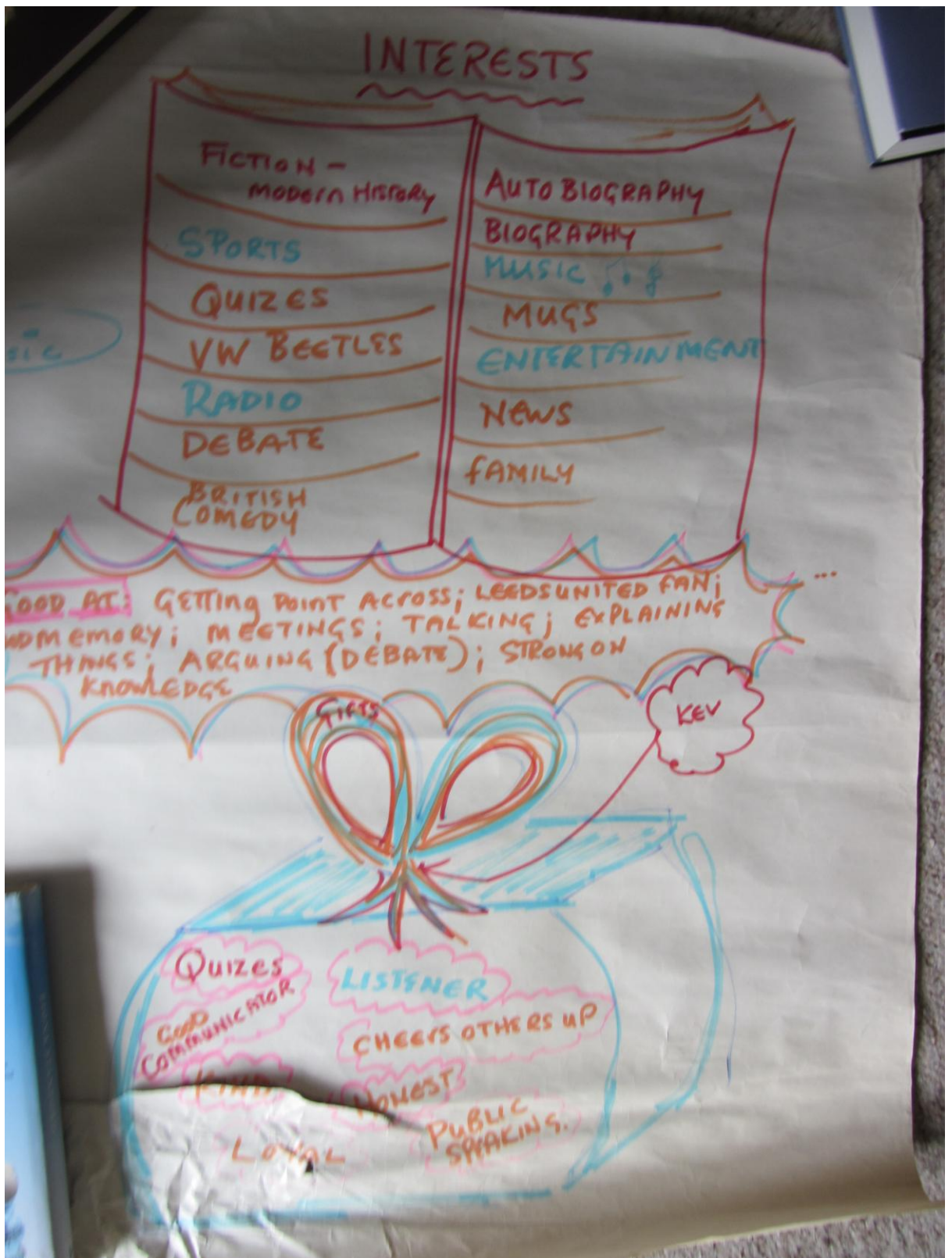


Respect Others Views

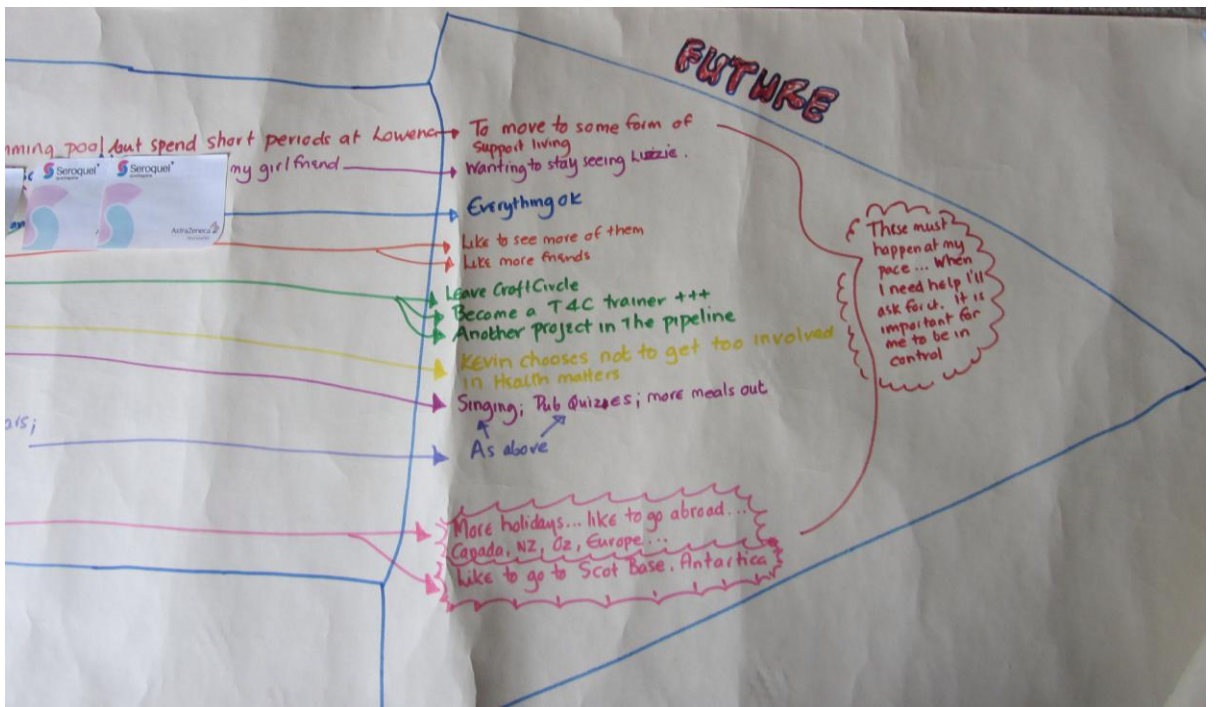
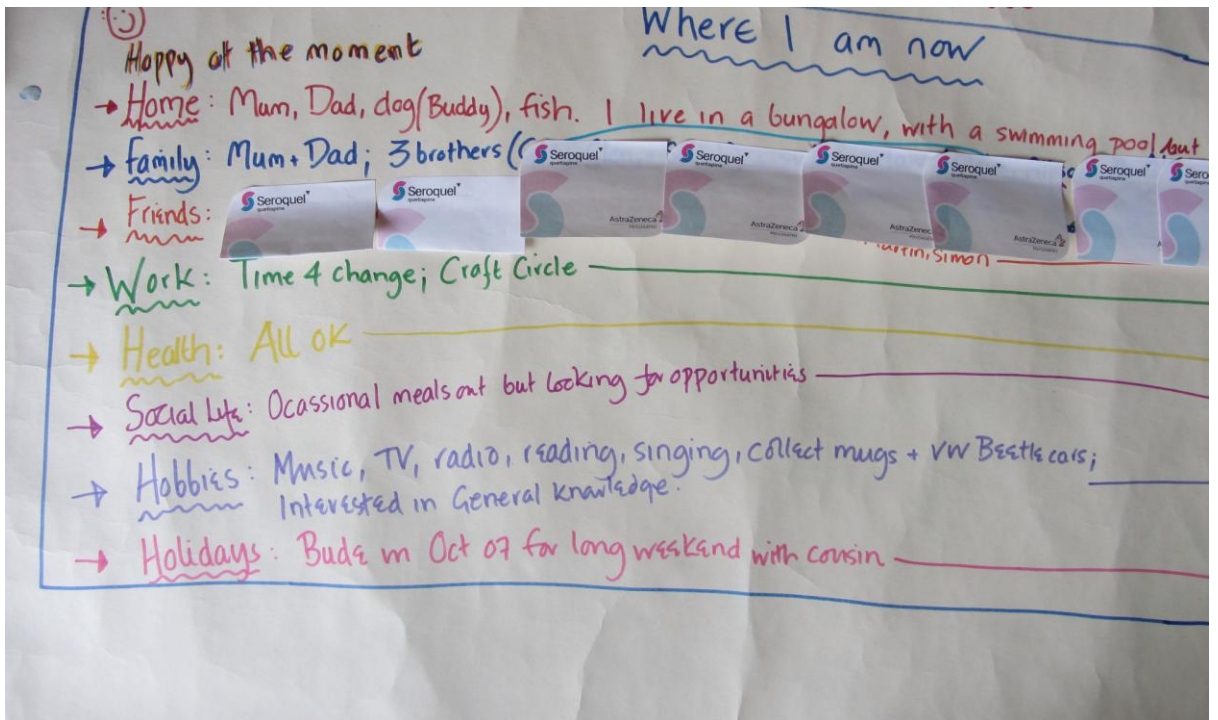


C.Millard 12th July 2010 Version 1 ref10/H0107/53

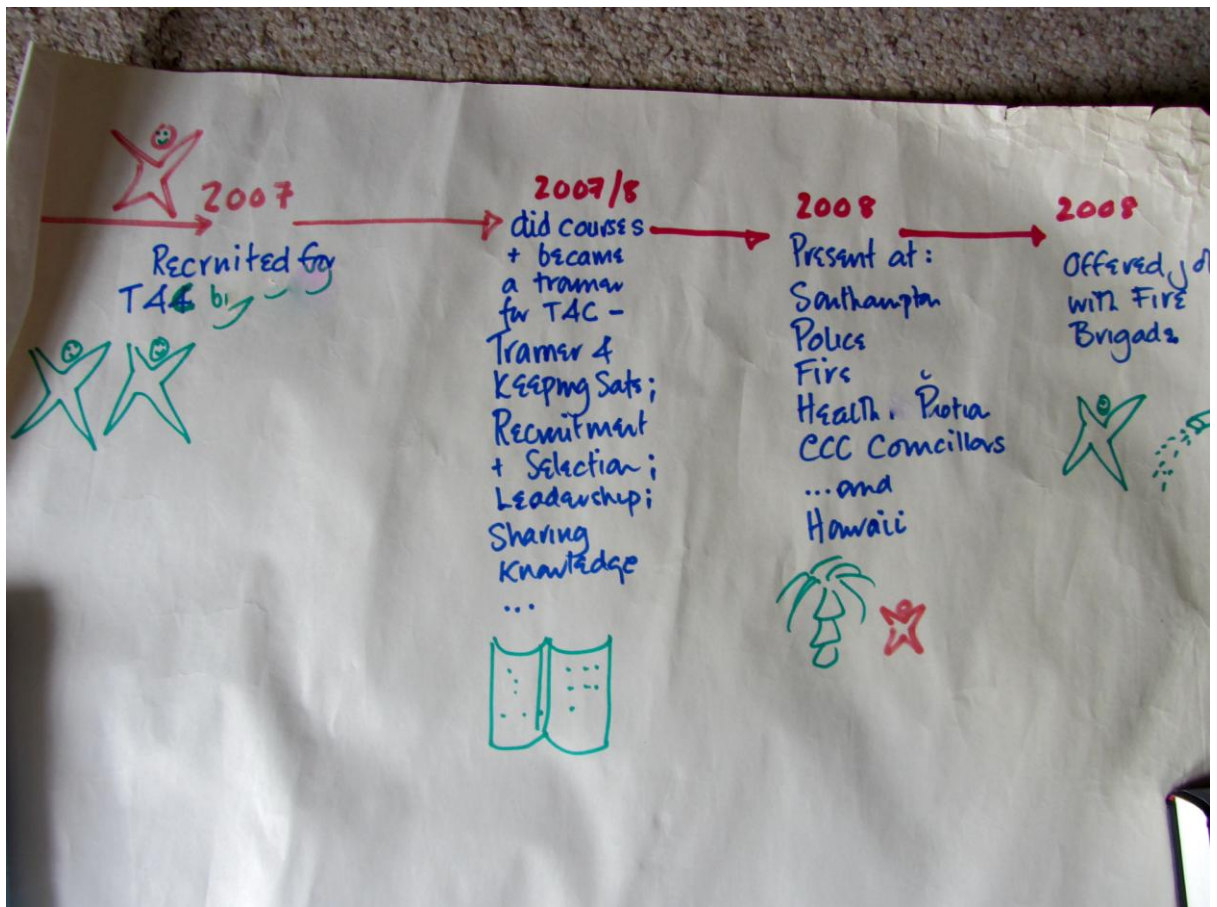
Appendix 5 Keith's person centred planning graphics.
Interests and gifts.



P.A.T.H.



Keith's Achievements and journey.



Appendix 6 University and NHS approval forms.

STUDENT HIGHER-LEVEL RESEARCH


UNIVERSITY OF EXETER
Graduate School of Education

Certificate of ethical research approval

STUDENT RESEARCH/FIELDWORK/CASEWORK AND DISSERTATION/THESIS
You will need to complete this certificate when you undertake a piece of higher-level research (e.g. Masters, PhD, EdD level).

To activate this certificate you need to first sign it yourself, and then have it signed by your supervisor and finally by the Chair of the School's Ethics Committee.

For further information on ethical educational research access the guidelines on the BERA web site: <http://www.bera.ac.uk/blog/category/publications/guidelines/> and view the School's statement on the 'Student Documents' web site.

READ THIS FORM CAREFULLY AND THEN COMPLETE IT ON YOUR COMPUTER (the form will expand to contain the text you enter). **DO NOT COMPLETE BY HAND**

Your name: Mr Christopher Millard

Your student no: 570038339

Return address for this certificate: Lanrose, Broad Lane, Godolphin, Breage, Helston TR13 9QX, Cornwall.

Degree/Programme of Study: Ed.D. (Special Educational Needs).

Project Supervisor(s): Dr Phil Tayliss and Dr Hazel Lawson

Your email address: Home: Hursmore@btinternet.com,
Work: Chris.millard@cft.cornwall.nhs.uk

Tel: Home: 01736 761992 Work: 01872 358734

I hereby certify that I will abide by the details given overleaf and that I undertake in my dissertation / thesis (delete whichever is inappropriate) to respect the dignity and privacy of those participating in this research.

I confirm that if my research should change radically, I will complete a further form.

Signed:  **date:** 15.7.2010

***NB** For Master's dissertations, which are marked blind, this first page must **not be included** in your work. It can be kept for your records.*

Chair of the School's Ethics Committee
last updated: August 2009

Certificate of ethical research approval

Your student no: 570038339

Title of your project: An Investigation into the Authenticity of Person Centred Planning for People with Learning Disabilities.

Brief description of your research project.

Person centred planning should be viewed in the context of humanistic and existential explanations of how humans relate to each other and their communities. Rather than operating on a singular field they operate within a contextual framework that is complex, rhizomatous and explicitly linked with how individuals view themselves and how others view them. There has been very little emphasis on what individuals experience as part of the process, or what happens to their lives as a result. This proposed study will examine self determination and aspirational thought and deed within the process of person centred planning. The research approach is grounded partly within an existential and metaphysical philosophical framework. Post positive methodologies which include Participatory Action Research and Visual Ethnography will be utilised in order to compare the relationships and examine connections operating within circles of support, and the wider process of person centred planning. The humanistic perspectives will hopefully lead to conclusions related to the effectiveness of person centred planning in promoting social inclusion, individual empowerment and aspirational methods of service design, and life planning for people with learning disabilities. It has been decided not to use any quantitative methodologies. This is largely because quantitative methods concentrate on what is observable and provable, and what causes individual variation. As a result they miss or reject the softer views of individuals. The core issue here is not what the researcher thinks about the process but what the individuals feel, think, and do both collectively and individually within the circle of support. Also how do these relate to the wider concept of person centred planning for the person they have chosen to support (Kalof et al., 2008).

The research will focus directly on circles of support, incorporating very active circles of support which link locally and nationally to personalisation networks organised by the Department of Health Valuing People Support Team.

Chair of the School's Ethics Committee
last updated: August 2009

Participants will be recruited from existing circles of support, visual ethnographic and action research methods will be utilised involving the participants.

A circle of support meeting will be video taped, and a twenty minute extract prepared by the researcher incorporating the beginning, middle and end of the meeting. The video extract will be played to individual consenting participants and this will provide the basis of a research interview. This conversation will be recorded and analysed using discourse analysis, and a suitable ethnographic software package for example NVIVO. A research diary will be kept and an audit trail developed including raw data, interviews, photos, field notes etc to capture the detail necessary in a small scale study. Negative case analysis will also be used where the researcher will actively look for occurrences that disprove any hypothesis developed (Denzin, 1988, Elliot, 2007). It is also recognised that the researcher and participants may well have pre-existing views about the study area. These will need to be discussed in initial sessions and compromises and decisions reached.

Give details of the participants in this research (giving ages of any children and/or young people involved):

The researcher will involve one full circle of support (most circles consist of 3-10 persons), but it is hoped to recruit two circles of support in total to cover unexpected eventualities for example, in case someone decides not to participate, or becomes ill. Only individuals who can give informed consent will be included in the research. The individual supported by the circle should use learning disability services, and be an adult of 18 years or older. It is proposed developing a peer debriefing and checking group with fellow researchers to ensure validity and rigour. Also to provide all the circle members with any copies and transcripts of each session. These will then be used in the next session as a basis for discussion and formulation of research focus and questions. A depth rather than breadth approach is to be taken in this study since small number of participants are proposed.

Give details regarding the ethical issues of informed consent, anonymity and confidentiality (with special reference to any children or those with special needs) a blank consent form can be downloaded from the SELL student access on-line documents

The researcher will at all times respect individual views ensure that they are listened to and acted upon and ensure that communication methods are utilised that promote full participation and are the preferred method of communication for individuals. All research material will be anonymised with individuals deciding how any material is presented and to what audience. Individuals' diversity will be respected in terms of their age, race, culture, ethnicity, sexual orientation and socio-economic status. All participants will be free to withdraw at any time and will never be subject to coercion. Group rules will be decided at the first meeting, (an example is included in this application)

The main aim will be to follow the Economic and Social Research Councils six key principles:

- All research should have integrity and quality.
- All research staff and participants should be fully informed about, the purpose, methods and intended uses of the research. What their participation involves, and any possible risks.
- All information supplied by participants should be confidential, and anonymity should be guaranteed.
- All participants should be free from coercion.
- Harm should be avoided.
- The research should be independent and any conflicts of interest made explicit.

Also any written material will need to be produced in a communication that is the preferred method for the individual concerned. Easy to read and understand information will be provided this will include information sheets, consent forms and any other material required by participant. This may involve the production of taped instructions or the use of assisted technology learning packages.

Give details of the methods to be used for data collection and analysis and how you would ensure they do not cause any harm, detriment or unreasonable stress:

The main tenant of any ethical approach is to do no wrong, or to do the greatest good(Todd, 2005). It is not in anyone's interests to cause harm or otherwise adversely affect a research participant. However, safety for the researcher should also be considered for example is there risk or threat or abuse, psychological trauma as a result of what is disclosed during the research, or the risk of being in a compromising situation(Craig et al., 2000). If at any stage any participant shows signs of distress or harm they will cease to be included in the study but, relevant help and support will be sought to assist them in their difficulties, including professional help should it be required. Since the research methodology and research design is based on participatory research approaches, individuals consent will be sought before any video, picture or audio recording is used. The participants will also be involved in deciding how the research is finally disseminated and what media is used. At all times individuals names will be anonymised, and no confidential data used or data that the individual focussed person, or circle of support members find distressing or contentious.

Give details of any other ethical issues which may arise from this project (e.g. secure storage of videos/recorded interviews/photos/completed questionnaires or special arrangements made for participants with special needs etc.):

All material will be stored in a locked filing cabinet, and any visual/audio data will be stored on an encrypted hard drive. Copyright for photos will be retained by the originator. All material will be anonymised and destroyed at the end of the study. No material or data will be used in the study unless all of the participants give informed consent.

Give details of any exceptional factors, which may raise ethical issues (e.g. potential political or ideological conflicts which may pose danger or harm to participants):

There are no exceptional factors anticipated with this proposed study.

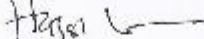
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TODD, M. (2005) *Ethical issues in Todd, M and Gilbert, T Learning Disabilities; Practice issues in health settings*, Abingdon. Routledge.

This form should now be printed out, signed by you on the first page and sent to your supervisor to sign. Your supervisor will forward this document to the School's **Research Support Office** for the Chair of the School's Ethics Committee to countersign. A unique approval reference will be added and this certificate will be returned to you to be included at the back of your dissertation/thesis.

N.B. You should not start the fieldwork part of the project until you have the signature of your supervisor

This project has been approved for the period: July 2010 **until:** February 2011

By (above mentioned supervisor's signature):  **date:** 15/7/10

N.B. To Supervisor: Please ensure that ethical issues are addressed annually in your report and if any changes in the research occurs a further form is completed.

SELL unique approval reference:..... D/27/10/28.....

Signed:  **date:** 16/07/2010
Chair of the School's Ethics Committee

This form is available from <http://education.coe.ac.uk/studen/>

Chair of the School's Ethics Committee
last updated: August 2009



National Research Ethics Service

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05 January 2011

Mr Christopher J. Millard
Lanrose,
Broad Lane,
Godolphin,
Breage,
Helston,
Cornwall
TR13 9QX

Dear Mr Millard

Study Title: An Investigation into the Authenticity of Person Centred Planning with People with Learning Disabilities.
REC reference number: 10/H0107/53

Thank you for your letter of 18 December 2010, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by the Chair on behalf of the REC.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

This Research Ethics Committee is an advisory committee to South West Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>

Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Protocol	1	15 July 2010
Response to Request for Further Information		28 November 2010
Response to Request for Further Information		18 December 2010
Covering Letter		18 December 2010
Letter of invitation to participant	2	28 November 2010
Participant Consent Form: Photo consent	2	28 November 2010
Participant Consent Form: Video	3	17 December 2010
Participant Consent Form	3	17 December 2010
Academic Supervisor CV		15 July 2010
PREP profile		15 July 2010
Requirements and Presentation of a thesis		
Rules for meetings	1	01 July 2010
Investigator CV		15 July 2010
Participant Information Sheet	2	28 December 2010
Participant Consent Form	2	28 November 2010
Participant Consent Form: Video consent	2	28 November 2010
Participant Consent Form: Pictorial	3	17 December 2010
Participant Consent Form: Photo	3	17 December 2010
Advertisement		
Evidence of insurance or indemnity		17 August 2009
Referees or other scientific critique report		01 November 2009
Referees or other scientific critique report		17 November 2009
REC application		
Dr P Bayliss CV		27 June 2010
Letter from supervisor		15 July 2010
Corwall criteria for use of IMCA Service		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk

10/H0107/53**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

pp. 
Dr Mike Shere
Chair

Email: middleton@nhs.net

Enclosures:
Copy to:

"After ethical review – guidance for researchers" sent via e-mail
Dr Philip Bayliss

Appendix 7 Interview transcriptions

Keith and Susan's Transcript: Two sessions at Keith's flat 16th June 2011 (1.5 hours long K1-K18) & 17th June 2011(1.5. hours long K18- K 28).

Chris, Well Keith and Susan we have talked about what this research is about and I would like to know what you think and feel when I showed you these small clips from the big meeting. So what did you both think?

K1. Keith. Well first of all I thought I was controlling the meeting well, um well obviously we were trying to sort out a problem mum had her view I had mine. I thought it was a bit of a battle there, but we managed to sort it out between us.mum was sort of saying I couldn't have me day out and I thought, well I can if the (name omitted)want me they will have to provide transport and stuff.

Chris. and what did you think the rest of the group thought about that?

K2. Keith a lot of them were in agreement I think. **Chris** so in the end what happened? **Keith.** We all agreed with my way of thinking which I thought was very good. I will admit I have always been cynical of circle meetings, and having people there, but I wouldn't be without my circle they really do a good job. **Chris.** So can you say why you have changed the way you think about the meetings?

K3. Keith I guess it's because I have the right sort of people around me, who think the same way I do. When I wrote down my first list of friends I turned to Charlotte and said I am going to have to hire the Mormon Tabernacle Hall in blooming Tallahassee or wherever they hang out. It's not like that you just have a small group of people and you just discuss what we want to do basically. **Chris.** What is it about the people in the group that want you to have them in the group?

K4. Keith. Well they know me and what I want basically. I like people to be quite cheerful, and you are all quite cheerful people. You listen to what I say and you don't nag me to death, which is why I chose you really. You all seem to talk a lot of sense. **Chris.** Ok What about you Susan what do you think about it?

K5.Susan. I was a little bit nervous. **Chris.** Why was that then? **Susan.** Because of the video. **Chris.** You know all the people don't you?

K6. Susan yes I know all of them(Susan lists the names of everyone)? **Chris** so what did you think was going on in that bit of the meeting? What did you think we were doing? **Susan.** Talking and sorting things out. **Chris** and did you think we did it? **Susan** yes I did **Keith** stopped people talking too much. **Chris.** Well that's useful

isn't it. **Susan** yes. Keith also agrees. **Chris**. Is there anything either of you want to say before we see the next bit?

K7.Keith I can't think of anything really, things are going pretty well its nice , I like the idea of somebody else coming like an outsider from the family coming, and giving a different view, and mum latching on to that different view. **Chris**. That's interesting so when you say the family, who is the family? **Keith** mum and dad. **Chris** but you have brother don't you? Keith yes but I wouldn't have them at my circle meeting. Chris. Do you want to say why that is or would you rather not talk about it? I can assure you its confidential but will go into the final report.

K8. Keith. That's ok I never ever see them and when I do they nag me to death. I'm not having that.(remaining conversation omitted)Chris how does that make you feel? Keith. Well it saddens me a bit, but I think it would be nice if they rang me up for half an hour, like we have a chat for half an hour. One of my brothers phones me but the other two don't. One was supposed to connect my tellie, but it was three weeks after because he had forgot to do it. That's why I won't have them in my circle.

K9.Susan you said there was a bit in the video when Keith stopped somebody talking can you remember that? Keith yes i stopped them because somebody else made a comment. **Chris**. Can you remember Susan what you wanted to say? Susan laughing I can't remember Chris, I can't remember. **Chris**. Ok shall we look at the next bit then?

K10. Susan. Quite good actually. **Chris**. In what way was it good then Susan? Susan. When Keith came out with black sheep. **Chris**. Do you know what that means? **Susan** No. **Keith** well it means if somebody eh, if you are a family member and you go away, I'll let Chris explain. **Chris**. No you say Keith because you said it. **Keith**. It means you're the renegade of the family, and they don't want to know you for a while, and you get shut out of things when you are supposed to be a family member. **Chris**. So what else about that Susan somebody walked through didn't they? **Susan**. Yes Buddy the dog. **Chris**. So not only do we have humans, but we have a dog as well. Is that important?

K11.Keith. Yes very important because li have grown up with animals all my life, so it's nice we've got animals wandering around. **Chris**. can you explain who is buddy? **Keith**. He is a black and white collie rescue dog my brother used to have him, and we took him on. I think he is about nine years old, and daft as a brush

really. Chris. so that bit of video Susan said was ok, what about you Keith what did you think?

K12.Keith. Pretty good I can see mum pushing for me to stay in. Dads coming onto my side, but mum is pushing for the (service name omitted) in other words. **Chris.** Do you think that's what was happening Susan? Susan. Yes. **Chris** so what else was going on there?

K13. Keith. I don't really know, I guess its trying to problem solve. **Chris** and what does that mean? **Keith.** It means you've got a big problem, and you are trying to diffuse the main problem. You are trying to get rid of the nuisance, or look at or give a different approach in other words. **Chris.** and did it sort the problem out for you? **Keith** It did actually because when li went to the meeting he was very apologetic and asked me what was bugging me, and I said they were there was a certain member that I didn't get on with at all and that's when it all stopped. I don't want to go into too much detail. **Chris.** But you sorted it out and were happy with what happened? **Keith** Yes. **Chris.** You said some things on there that I thought were quite interesting, one of them was I don't want to let you down Mum and Dad do you want to say a bit about that?

K14. Keith I have always set my standards by dads standards, and have always tried to live as dad lived, because I have this job and my dad is an ex serviceman. So I was a bit reluctant to leave anyway. My family has a long tradition of being in services, but although I didn't want to leave, I didn't want to be used at the same time. **Chris.** and the other thing was towards the end you said I want the circle to vote on it and Janet said no you are the most important person or something like that you need to tell us what you want to do. How do you feel about that?

K15.Keith Umm I guess the reason I said to vote was because I needed to know one way or the other, I like to know what I am doing. I like to forge my way forwards with a bit of help. I go through life wearing like a pair of armbands, and I use that as an armband support basically, because I didn't know what to say. That's why I said we need a vote on it really. **Chris.** So you meant for the group to help you but not actually say you have got to do this?

K16.Keith. Yes that's how I see the group working, basically they give me some guidance and advice on where I should go next. **Chris.**I know you were not

very keen to have the meeting, and you phoned me a few times didn't you. Can you say what that worry was about?

K17.Keith. Well I guess it was because I thought other students would be listening to my thoughts who I didn't even know or whatever, and they probably are...**Chris.** no one at the University will hear this except my supervisors, and I would only let them hear stuff I think I am having problems with ok. I want to reassure you.
Keith ok. **Chris** and when I write it up, if I think it's really sensitive stuff, and likely to upset people I won't put in people's names or services. Does that reassure you?
Keith yes its fine. **Chris.** Susan have you got a circle of support.

K18.Susan. Yes I have . **Chris.** Is it like Keith's? **Susan.** At the moment I am working on mine. **Chris.** Perhaps that's one of the things we can sort out from doing this, because we spoke about having a joint meeting didn't we? **Keith** yes we can do that anyway, because we want to do more or less the same things together anyway.
Chris. What about the next clip what did you think about that?

K.19. Keith It's a bit of light relief really from the serious stuff. One thing I have noticed is that dad is sitting there taking it all in but not actually joining in.
Chris. Why do you think that was?

K20.Keith. I don't know really I guess he thinks mum has done everything for me, and he has kind of been in the background all my life. **Chris** why because your mum cared for you.? **Keith** yes mum did everything for me basically, but since I have moved, me and my dad have become a lot closer. **Chris.** What way have you become close? **Keith.** Well we just ring each other up were not in each other's pockets all the time, we don't get fraught or shout at one other very often. We just have a general chat, and he's told me stuff about other family members that's quite good. He never used to discuss things like that with me. Now we have a serious chat. Sometimes he will come over here and watch a big football match with me.
Chris. Susan what did you think about that bit of the meeting?

K21.Susan. Not bad . **Keith.** That meeting was a kind of birthday party as well. **Chris** do you think that's important, the pair of you? **Keith.** Yeah it's got to be casual anyway. **Susan.** It's nice to have fun. **Chris.** What did you think about what your dad said to you about the lady fiddling with your shower. I think he said you've got to put up with these things.

K22. Keith. I was a little bit surprised he said that, because I thought he would have backed me as I was looking at the safety aspects of it. The group then took it up and sorted it.

Ok shall we see the next bit then? **Keith** and **Susan**. Yeah.

K23. Keith. One thing I noticed was the way Dawn came across. The oasis in the whole storm like. Nothing seemed to phase her or anything. **Chris.** What do you mean the oasis tell me about that? She always seems to diffuse the situation, and make it a lot calmer that's what it could be you know. The way she puts things across I mean. **Chris.** Tell me about the way she puts things across? Just calmly and soothingly she doesn't put people backs up. **Chris** so she gives you good advice? **Keith** Yeah. **Chris** what about the circle.

K24. Keith Brilliant they give me good advice. I wouldn't be without them now. **Chris** yes because to begin with you were not sure? **Keith** yes I was very wary. **Chris.** Do you want to say why that was? **Keith.** Well I was always brought up not to air my problems in public, and not bother people with my problems, and just muddle through on my own. It's nice that we call a meeting and we sort a lot of stuff out. **Chris,** so when the group says we are going to do such and such does it do it? **Keith** yes , oh yes. **Chris.** And what about in the past were you let down at all?

K25. Keith back in the long distance past yeah, we had an incident about 18mths ago when we all locked together, and were rock solid and sorted the whole thing out. **Chris** do you want to explain what the incident was? **Keith.** Basically someone in (service name omitted) decided I didn't have a learning disability. **Chris** can you explain how they did that? **Keith.** Well they came to a meeting and dad said could they bring a (name omitted) because we wanted direct payment, and they turned up didn't say good morning, just sat down and said "hello Keith you haven't got a learning disability" and we were in shock. I nearly fainted I knew we would get out of it but it was a long protracted struggle really. **Chris** How did you know we would get out of it?

K26.Keith. I guess because I had the right support, and people knew where to go, and I knew that I had to fight to clear my name in some respects **Chris.** Clear your name can you say what that means. **Keith.** Yeah it means that I had been in the same service for as long as I could remember, and I felt the person was making me a pariah and wiping his hands clean of me and my problems by fobbing me off to somebody else. I think when I met the person from the (name omitted) service she

realised I had a learning disability. **Chris** so how did they find out you had a learning disability. I went to (name omitted), and did a few tests, and they discovered I had an I.Q of 69 so I just made the cut off point. **Chris** so shall we talk about some nice things just to finish, **Keith** yeah. You mentioned we have been to Hawaii twice what did you think about that?

K27. Keith Excellent I would go again tomorrow if I had the chance. It's really paradise on earth. **Chris** and what did you do there then? **Keith** we talked about health facilitation in (name omitted) the first year, and person centred planning the second year. I think we both preferred the second year 'cos we had a bit more time, and we could do what we wanted, seven days was a bit much. It was a good experience and I was glad I went. **Chris** and that happened because it was one of your dreams? **Keith**, Yes basically I am very lucky I am a trend setter. Susan. What did you think of it all?

K28. Susan I have been taking it all in. **Chris**. Do you think person centred planning is a good thing or not ? Susan. Yes i think it is a good thing. **Chris** in what way then is it a good thing? **Susan**. Its helped Keith a lot. **Chris**. Do you think if it works for Keith it could work for you? Yes I think it will. **Chris**. Is there anything else either of you want to say before I stop the recording. **Keith**. Can't think of anything. **Chris**. Thank you both very much I know how difficult this is, not an easy thing to do.

Circle Meeting Video Transcript. 6th April 2011.

Venue Keith's parents home. Length of meeting 2.5hrs.

T1.Keith opened the meeting. Right were waiting for Cecil be Demill to get set up. **Chris** I'm doing it now.

Keith. We are going to discuss the (name omitted) Mum you had a worry what was that. **Sharon.** The only thing that concerns me if he doesn't do what the (name omitted) want, **Dawn.**(Mentions person's name), he was given the (name omitted) funding. I did ask if he wasn't going to the (name omitted) some of the time could he use it for other things and they did say yes, but I only have that in word of mouth, not in writing. **Dawn:** so (name omitted) hours cost the same as the days he had at (name omitted).They will never come and ask you Sharon. **Keith:** No the're my hours they can't take them away. **Sharon:** as you know he's saved up quite a lot of time. **Dawn:** he would have to do a reassessment, and follow the whole process. It's not attached, the reason we wanted it, is so Keith can do independent living and the (name omitted) days.

T2. Keith : The thing that bothers me about all this, is that I didn't hear from them for months and months, why are they suddenly interested in me again?

Charlotte:Because they have got an inspection coming up, **Keith:** yes exactly.

Dawn: I know why they are interested in getting Keith, because they want the safe places stickers in all the (name omitted), because it makes them look good. So they want you to go around and give talks about safe places which is something you don't really know about is it? **Keith:** They asked me to go out on another job when they were doing the training for that, so I missed out on the training. **Dawn:** number one all the guys in the group have done the training you haven't, number two when you have gone around all the (name omitted)talking about learning disability, and once that was done it stopped. I think what we should ask for is a 12 month programme.

Sharon: (Mentions person name) was saying**Keith:** hang on Charlotte made a point there. **Charlotte:** I think you need to be picked up. That's your pleasure time isn't it. **Keith:** I don't see why I should give up my (name omitted). I want to use those for other stuff. **Sharon** the only thing when he gets this day it's called a discretionary payment. **Dawn:** What Keith was getting from (name omitted) was three days at (name omitted),**Sharon:** but it's not coming out of the same budget

now. **Dawn:** That's just them fiddling their system. **Sharon:** It's coming out of a discretionary payment, whatever that is I have no idea. **Janet:** I shouldn't think that should concern you, it's about what hours Keith has been assessed as needing not what pot the money comes out of, shouldn't stop the..... **Sharon:** well its only 7hrs a week. **Keith:** I'm limited at what I can do, so I feel that if the (name omitted) want me they should provide transport. **Dawn:** What going to happen as far that's concerned is that Keith will be assessed and get his individual budget. What he does with that is upto him anyway. When Keith's next assessment comes up that's the way it will go anyway.

T3.Keith: (looking at Sharon) I will always consult you and dad . I hear nothing for months and then I get a phone call saying oh can you do this for us, can you do that. **Charlotte:** Who made the phone call Keith? **Keith:** I rang (name omitted) to ask if he wanted to come to this meeting and he said do you want to do this? But the thing is he is retiring, so I will be back to square one again if he leaves. **Sharon:** who is the man he said he was going to assign to you. **Keith:** says person's name. **Dawn:** I had a telephone call from him ,but it was when I wasn't in the office. I have got his number to ring him back but I wanted to talk to everybody first before I had a conversation with him. **Sharon:** I have not spoken to (name omitted) I have only spoken to (name omitted) she said (name omitted)they thought that Keith went to (name omitted), and he is furious with (name omitted), who took Keith over originally. **Dawn:** Before that (name omitted) rang me, and said this that and the other for Keith, so I said you need to ring Keith. It's been pushed around and we don't know what is going on. **Sharon:** I used to think (name omitted) was lovely. **Keith:** I like (says person's name). **Sharon:** He came the day before Christmas Eve with a car for Keith, and he said is Keith in, and I said no he doesn't live here now. He has his own place at (name omitted) he said I haven't got time to see him now but I will go after Christmas, he's never been near. **Janet:** Did you get your card Keith. **Keith:** yes mum gave it me.

T4.Keith: I just feel do I want to put myself through all that disappointment again. **Sharon:** It's up to you. **Dawn:** What they want is (name omitted) to go around all the (name omitted), and do safe places because they want me to do it with you. But that is not how we work, they need to pay us and they are not prepared to do that, so they are trying to do it without paying us. They need to support your transport, support you with somebody when you are there, make sure you have got

the equipment you need, and PowerPoint presentation, and that all sorted out.

Keith: But they won't do that. I just want some advice from you guys I think we should take a vote on this.

T5.Janet:Your the first person that needs to vote don't you. **Dawn:** It's up to you Keith. **Keith:** Do I really want to put myself through all this disappointment again. **Dawn:** This is just a suggestion shall I speak with (name omitted), I know we have done this before but I'm happy if we go and have a conversation with him, but you need to really honest and tell him exactly how you are feeling. **Keith:** I feel used to be honest. **Charlotte:** You need to get a contract with him. **Keith:** Trouble is I don't like to go in all bolshie. **Dawn:** It's not about being bolshie, it's about being honest and I think they need a dose of honesty. I think you are within your rights to say you are disappointed. **Charlotte:** You'd do ok if Deb was with you. **Keith:** Yeah. **Dawn:** and you'd say it to me wouldn't you. I will be there to support you, but you will have to say how you feel. **Keith:** The only thing is I will let people down, and that's the last thing I want to do. **Charlotte:** They've let you down Keith. **Nigel** They've let you down badly.

T6.Keith: What do you honestly think I should do Dad? **Tom:** I would let them come to you personally, that's how I feel about it. They've messed you about for such a long time. I would sit back and wait and see what happens. **Keith:** Well we know I can't lose my seven hours. I can do what I want with them. **Tom:** Just wait and see what happens. **Keith:** I can't see anything happening at all. **Dawn:** I think what will happen is, they will ring me. **Janet:** And what will you say Deb? **Dawn:** I will say this is Keith's telephone number, ring it and discuss it with him. **Keith:** I'm quite happy doing what I am doing now. **Dawn:** Keith weren't you going out to have a meal with him. **Keith:** He did say about me ringing him next week. **Charlotte:** What about him ringing you. **Nigel:** I should let him ring you. **Keith:** I will leave it then. **Tom:** Don't run after them all the time Keith. **Keith:** I'm just wondering if I want to go all through that hassle again. **Tom:** That's up to you. You have to make up your own mind as far as that's concerned.

T7.Keith: Trouble is if I say no mum and you will be disappointed. **Tom:** No, no it's your life. You've got to start planning things on your own really. **Sharon:** But if they can find something for you, you do enjoy it don't you. **Charlotte:** They just can't pick you up, and drop you. **Dawn:** If they want you to do the safe places, obviously I will work with you to develop the presentation, but I am not going to do it with you. If

Keith is part of the team they need to take some responsibility. **Charlotte:** Yes part of the family. **Keith:** Well this family member feels like a black sheep. **Janet:** laughs. **Dawn:** In the beginning (name omitted) did it with the best intentions, I don't think he actually thought about it, or realised what it meant. I don't think he looked at the whole picture. I think that's a shame, but it was all done with the best intentions. **Keith:** Yeah he did, but he didn't realise what the other blokes had been like. I trained them they weren't prepared for what I did to be honest. I'll do what Dad said, I will wait until he rings me. **Tom:** leave the ball in their court Keith. **Charlotte:** I just think they wheel him in, and wheel him out again. **Dawn:** This is part of your training Keith, it's about getting them to know how to support you in the right way. It's not just about ticking a box. **Keith:** The day I was supposed to do the training, I was called away to a presentation, and really I need not have been there. If they want me to do the safe places, I am going in blindfold as I was called away on other jobs. **Dawn:** I can support you with safe places, we can put a PowerPoint together that's a really easy part of it, but they need to make sure that they support you to deliver it, and they support you in the right way. **Keith:** Charlotte said the right thing they should pick me up and help me out with this. **Charlotte:** Yes they should. You are doing them a favour. How many (name omitted) have you got there that don't get paid. Everybody gets paid, you don't though. **Dawn:** All you are asking for is a little bit of respect, you're not asking for the moon.

T8. Keith: if he rings I will tell him I want a meeting in the office, and I will bring Dawn with me. I don't want it to spoil our friendship though. **Charlotte:** It won't. **Nigel:** They will respect what you are saying. Sharon (name omitted) said to me (name omitted) will champion him more when he's out of the job than when he's in it, but I don't know what was meant by that. **Keith:** If he rings I will say I want a meeting in your office, and I will tell them how I am really feeling. **Charlotte:** That's a good idea. **Janet:** Yeah.

T8. Dawn: I feel every time I have a conversation with the (name omitted) they are trying to throw it back on me. That's how I feel. This is about their relationship with you. **Janet:** It's about their service Keith working for then. **Dawn:** Yes but if its though (name omitted) I will be charging them. That's why they aren't doing it through(name omitted). **Keith:** It's so, you know, I worked hard for them when I was working for them. **Janet:** So how long ago was that for Keith? **Keith:** I

must have done 18mths. **Sharon:** Yes 18mths -2 yrs, I should think. **Janet:** So how long since they didn't contact you Keith? **Keith:** A good year ins'nt it .

T9.Sharon: Ever since the restructuring. **Keith:** And that's taken years.

Charlotte: But he should have been part of that restructuring. If your part of their family, as they said. **Keith:** Well I feel like an orphan (laughing).(Everyone laughs). But the main thing I am worried about is disappointing you two (pointing to Sharon and Tom).**Sharon:** Now the only thing that concerned me, was that you would be disappointed if you lost(name omitted). **Keith:** But you now know I won't lose (name omitted). Dawn: you won't loose it for that reason. They don't know what you are using those hours for.

T10.Keith : I am watching the director at work look (pointing to the camera and myself.(All laugh). **Janet:** Have you got it written down what your hours are for. It must be there in the review meeting. I could have a look. **Dawn:** I think it's about it says for (name omitted) for support. **Keith:** I can use it for whatever I want to use it for. (At this point Keith leaves the meeting for a comfort break all conversation stops until he returns).

T11.Keith: Me and Susan had a laugh, we were having tea, and we got this woman about 25 or 26. **Charlotte:** Oh we hate old people(all laugh). **Keith:** Go on Susan you can tell them the story if you want. **Susan:** (Covering her mouth with her jumper) No you tell them. **Keith:** Well we were having our pudding, and she decided that the ice cream was so hard, she was going to stick the ice cream in the microwave.(a silent pause). **Dawn:** Were we supposed to laugh then? was that the punch line? **Keith:** Yeah. (Everyone laughs). **Dawn:** You can stick it in the microwave for a couple of seconds. **Janet:** Just to soften it. **Dawn:** Did she put it in for too long. **Keith:** Yeah, Yeah, we thought it was a bit odd. **Janet:** If you have a tub of ice cream, right out of the freezer you can do it. **Charlotte:** Nigel usually gets a knife and Chisels at it. **Dawn:** Charlotte just puts her head in the tub. (All laugh).

T12.Sharon: But the same lady did the bread rolls, and only put butter and filling in half of them. The others she left with nothing in. **Sharon:** When she pulled his bed cover back, she pulled it so the top cover was on the floor, and he couldn't cover himself up then. **Janet:** Who is this Keith? This is (name omitted) one of the staff at (name omitted). **Tom:** But these things will happen Keith, you just have to put up with them. **Keith:** The only thing that concerns me with her is, I have got the shower at the right temperature. **Tom:** I told you to tell her to leave it. **Sharon:** But

she won't Tom. **Keith:** It goes in one ear and out the other. **Tom:** Well tell her again Keith. **Charlotte:** Does she put it too hot or something? **Keith:** Yeah, and its dangerous. All the other staff leave it where it is. **Tom:** Just remind her. **Dawn:** Tell her, and if she doesn't listen tell the manager. **Keith:** Trouble is, if I say it too firmly she bursts into tears. She hasn't got a lot of confidence. **Dawn:** That's really not your problem. **Janet:** No it isn't, she's being paid to deliver the care properly, and safely. **Keith:** There's a lady called (name omitted) that me and Susan like, isn't that right Susan. (Susan continues reading her book). **Dawn:** Has the manager read your care plan? **Keith:** Not yet. **Dawn:** Well it might be good, to ask her to sit down and read it. **Keith:** There's (name omitted) and (name omitted), and they are brilliant aren't they Susan?(Susan laughs when Keith waves at her).

T13.Nigel: Do you test the water before you get in? **Keith:** Urrh well, not really because it's at the right.....**Nigel:** If the girl is fiddling with it, you need to test it before you jump in. **Sharon:** I always used to do it for him, before he got in. **Janet:** Is that in your care plan? I like the temperature on that mark, and nobody touch it. **Nigel:** But you can't guarantee that that is going to happen. So it's always best to put your hand in, and check its ok. **Tom:** Especially with cleaners going in, they may accidentally move it.

T14.Charlotte: Whenever I go to your flat, you say here's the carpet sweeper. **Sharon:** That shows he's given you a biscuit, or cake, or something. Everyone he give food too gets to clean the floor. (More laughter). **Keith:(smiling)** naughty aren't I ,bad. **Charlotte:** You still owe me a cake. **Keith:** I'll take you out one day, and I'll get you a cake. **Charlotte:** We had a bet didn't we. **Keith:** Yes Leeds United and Arsenal, and I thought Leeds would beat Arsenal, and they didn't. **Charlotte:** Course they didn't. (The group start laughing, and talking in separate conversations).

T15.Keith: Moving onto brighter stuff. I'm having a meeting tomorrow about a holiday to (name omitted).They are going to give me some dates and I've got the two staff I wanted. **Charlotte:** are you going to the 60's, 70's or 80's weekend? **Keith:** I'm not worried. **Janet:** There are different weekends . **Keith:** Susan is coming with me as well. **Nigel:** Which one are you going to?.**Keith:(name omitted).** **Sharon:** You see he's allowed 60 miles. Nobody picked him up all through the snow, which obviously they couldn't, but they still get paid. They had a couple of days when there was no staff to look after him. So they've added all the time up. Dawn: Do you know

how much time you've got Keith? just make sure you get it all. **Sharon:** They said there is enough to take him there, with two staff for four nights he only has to pay accommodation. **Charlotte:** He doesn't have to pay for their staff does he? **Sharon:** He has to pay for their accommodation. **Charlotte:** That's terrible. **Sharon:** Not their food though. If they go to a restaurant they have to pay for themselves. **Keith:** The reason I choose these two members of staff....Susan tell the circle why I choose them. **Susan:** No you can say it. **Sharon:** I don't really know why you choose them. **Keith:** They said to me we know you, so we won't charge you a lot. We are sharing a chalet. **Janet:**(says someone's name) . **Sharon:** They said we will fit in any time you want. We won't class it as extra hours if we are both with you. **Janet:** As far as the accommodation, you can sleep a minimum of four in the chalets. **Keith:** It's going to be, it's going to be, it's going to be a three bedroom chalet.

T16.Dawn: I think it's fantastic use of those hours. **Janet:** They keep a record of the hours which is good. **Sharon:** If they drop him off early they put in the book, they owe him an hour for that week. **Janet:** That's really good. **Keith:** And it's been suggested in the winter when there is nothing on during the day, they are going to start taking me out evenings. **Dawn:** No I think that will be a brilliant weekend. **Charlotte:** Sometimes they have things where carers can go free. **Sharon:** If he had gone with the holiday home, their carers go free I think you'll find.

T17.Keith: They rang me, but I'm not going to bother with (name omitted). **Janet:** Have you been there Keith? **Keith:** I've been for a look round. **Sharon:** They are very expensive. **Dawn:** There's a lot of activities there that are not appropriate for Keith like rock climbing and water skiing. **Janet:** Keith what you can do is go on the net, and see who is there for the dates you want. **Keith:** (name omitted) is doing that. **Janet:** Oh right. **Sharon:** Keith used to go on holiday with (name omitted) disabled charity. **Keith:** Then I got blacklisted. **Sharon:** Well you didn't get blacklisted, they reckoned he needed a 24hr a day carer. The last one we were offered, he was given 5 days for £600, and we had to pay £600 for the carer as well. **Charlotte:** I think that's awful. **Tom:** That's why he didn't go. **Keith:** All they ever did was go around charity shops for the day, its wrong isn't it. **Sharon:** That last time he went they went to a special hotel, and had been promised a down stairs bedroom, but he had to have a bedroom upstairs. **Keith:** I was in bed by 10 o'clock. **Sharon:** He had to be in bed by 10 o'clock, and the carer complained that she had to give him a cup of tea when he went to bed. **Charlotte:** We know about cups of tea

don't we. **Keith:** Laughing. **Charlotte:** Smiling. You're a bad man Keith. **Janet:** The weekend sounds really good Keith. The group start talking amongst their selves including Keith and Susan. **Keith:** If I go to (name omitted), can I take a few cans of beer? **Sharon:** Yes but you don't take them into the bar. The group laughs and continues talking generally. Keith looks at me so I say to the group, do you want me to stop filming now. All agree to continue a little longer.

T18.Dawn: Keith are you happy with everything in your life now? **Keith:** Oh yes. **Dawn:** Is there anything else we need to talk about. **Sharon:** I think we should say this is the first meeting we've had since he's moved out ,and we should say how well he has done. **Charlotte:** Triffic. **Janet:** You keep it very nice you're flat. **Keith:** Yes I try to keep it tidy. **Charlotte:** That's only because anyone who comes is given the carpet sweeper. All laugh. **Dawn:** That's not a bad move Keith. Its gone really well hasn't it Keith. **Keith:** It certainly has, I mean I don't feel quite so scared about living on my own now. I always have been a bit of a loner anyway. I like my own company. Susan comes over and sees me, and it's nice that all you guys keep in touch and stuff. Thanks to mum and dad I can still keep in touch with them three times a day. (All laugh). **Sharon:** I can't go on the computer now, every time I do I get Hello Mum. **Keith:** The Skype is a good way of keeping in touch though. **Charlotte:** I phone him one evening, and he said I am just on Skype watching Susan.Sshe is eating a great big steak and kidney pudding. (More laughter). **Sharon:** He'll say I've got (name omitted) say hello to my mum. **Keith:** I mean I do feel so comfortable with a lot of the staff there. **Sharon:** It is nice its worked out so well, seeing Keith is the first one for them as well.

T19.Keith: If they've got an appraisal form to fill in, its normally me who has to feel it in. **Dawn:** I think it's really positive that they ask you to fill out appraisals for the staff. **Sharon:** I think it was good when the fire man came around, and he had Keith with his wheelie, working out what would be good for the old people as well. **Keith:** I've got one of these doors that you can press a button and it goes back, and he's designed smoke alarms for disabled people. Where you just press a button to check it. He's looking for a patent for that. **Sharon:** You all know that Keith holds the fire door jam, and we were worried if the door came back it would take his fingers off. So this man came out ...**Keith:** I call him "Bobby Ball". (All laugh). **Sharon:** He went round with Keith and checked all the doors. The door in the lounge is awkward with the handle, and the wheelie. So that's now going to be an automatic door. **Keith:**

The manager has asked me to do all the voice recordings for (name omitted) when they close for the night, on their answer phone.

T20. Dawn: And you're doing some work around the care plans with them aren't you? **Sharon:** He's suggested to them, that everyone has a key worker, and he's explained to the manager that he does work with elderly people as well, because I have one with my mum. **Janet:** It's nice to have the one person who to speak to. **Charlotte:** It would be nice to have a circle meeting for older people as well.

T21. Janet: Yes anybody. **Charlotte:** You've got a box (looking at Dawn). **Janet:** A what? **Dawn:** My plan is in a box , and I use it for training with older people. **Sharon:** My mum's care worker was in (name omitted) and she would phone up and tell me what she wanted, she was good like that. That was nice. **Dawn:** I think it's been a really good move for you hasn't it Keith? **Keith:** Yeah. I feel a lot more confident in myself again. I can actually say no, you know it's like I always tell mum and dad what I am going to do. It's like basically, they were chuffed to bits when I was going to go around with the manager, and talk about (name omitted). It's not just for elderly people living in the flats. **Dawn:** When we talked about you living independently we were talking about 24hr care. Now you get 2.5hrs a day. **Janet:** You've got your own flat, but there is always somebody there in the background. **Sharon:** He's got his button to press. **Keith:** I've got me button here. **Sharon:** He forgot to take it off.

T22.Keith: I went back to (name omitted) last week, and they are thinking about setting up a friends of (name omitted). So they have asked me to join that. I also suggested that they need an advocate. So they are looking onto that as well, because that's the sort of thing I would like to do in future. If somebody with a disability had a problem I would find out what it is and negotiate. Be like the American secretary of State. **Charlotte:** What you want to be Hilary Clinton?(all laugh). **Keith:** No when he was ferrying during the Falklands war, between Argentina and the British Government, and that. That's the sort of advocacy work I want to do. **Dawn:** Mediation. **Keith:** Yes Mediation. **Janet:** Maybe (name omitted) advocacy, would be looking to use people with learning disabilities? **Dawn:** They have approached us in the past about people being on the committee, and people being involved. **Janet:** They developed it to employ people with learning disabilities as

advocates. **Keith:** I would work with Debs to the ends of the earth, she knows that.

Keith: I was a trustee for them for a year. I wouldn't go back to that.

T23. Keith: You know about the little problem I had. I want to be like the little boat that goes between the two harbours, people know me and I do my advocacy work with a smile. **Dawn:** I think it's a really good thing to speak about Keith because you use (name omitted). You use that service, you are in a better position than anybody to advocate for people who are still using it. **Keith:** When I spoke to the manager last week, she was very interested in what I had to say. **Charlotte:** Do they still call it wings and officers? It sounds like a prison. **Keith:** Yeah, well apparently they have got rid of officers, and all the wings have changed names. **Charlotte:** But wings and officers is prison language.

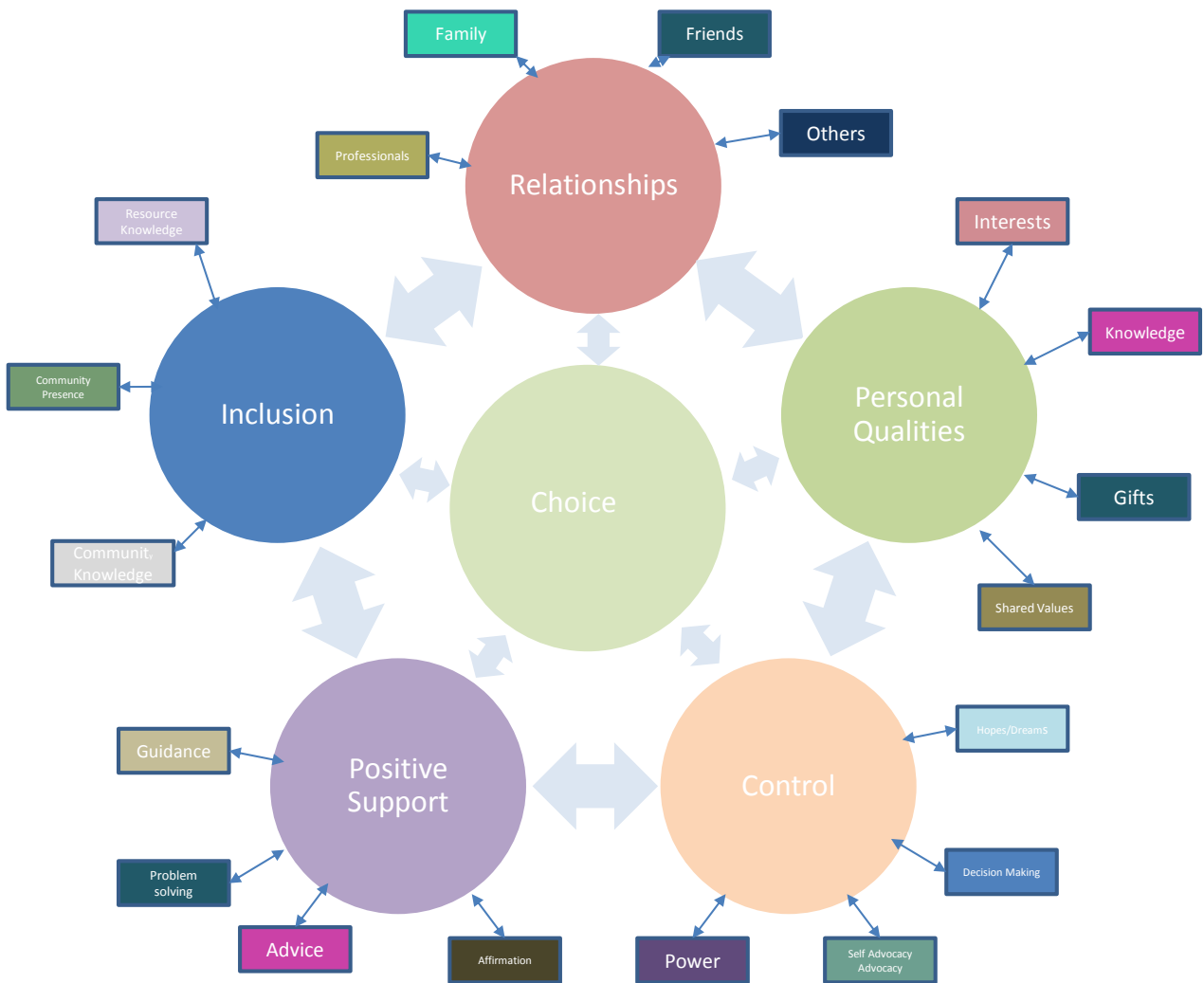
At this point the meeting started discussing some confidential issues so I stopped filming. The meeting concluded a few minutes later, and ended in a party celebration for Keith's successful move to his own flat.

Self instructions for Interviews.

- Explain that the research is about person centred planning and if it really does help people with learning disabilities get the life they would like.
- Three video clips will be shown and I am interested in what you think about them, for example what do you think is happening, I am interested in all the responses you get including feelings, things you remember as a result of watching the videos. Everything that comes to you. There are no right or wrong answers.
- I will maintain your anonymity at all times, all written, material will be anonymised.
- Feel free to interrupt, ask for clarification or ask for the interview to stop at any time.
- Are you happy with me tape recording the interview. I am going to use the recording to produce an interview transcription. I will use these to analyse the transcribed data, and use this in the research. No one else will hear the interview and I will destroy the tape after the study is completed.
- The study has been approved by the University and NHS Ethics committees.

Adapted from Loftland and Loftland(1984)

Appendix 8. Conceptual Model of attributes required for authentic person centred planning.



Appendix 9. Thematic development

2 Stage Thematic Development Across All Data.

Initial Themes		Primary Themes		Secondary Themes		
Pre Existent	Graphics (PCP'S)	Interviews	Interviews & Video	Conceptual	Main Theme	Sub Theme
5	16	19	52	1	5	19
PCP	PCP	PCP	PCP			
Choice	Choice	Choice	Choice	Choice		
Control	Control	Control	Control		Control	
Social Inclusion	Community presence	Community	Inclusion Acceptance Approval		Inclusion	Community Presence
Hopes/Dreams	Hopes/Dreams	Dreams	Enjoyment			Hopes/Dreams
	Personal qualities	Personal growth	Personal qualities		Personal qualities	
	Personal interests	Personal reflection	Personal reflection Commitment Confidence Working together			Interests
		Policies	Personal experience Individual knowledge Signposting			Knowledge

Initial Themes		Primary Themes		Secondary Themes		
Pre Existent	Graphics (PCP'S)	Interviews	Interviews & Video	Conceptual	Main Theme	Sub Theme
	Relationships	Relationships	Relationships		Relationships	
	Equality	Power	Power			Power
		Affirmation	Affirmation			Affirmation
		Positive support	Positive support		Positive Support	
	Friendships	Friendships	Friends			Friends
		Family	Family			Family
		Professionals	Paid/unpaid			Professionals
	Gifts		Gifts Individual qualities			Gifts
	Self Advocacy/Advocacy	Development	Autonomy Empowerment Assertiveness			Self advocacy/ Advocacy
			Sorting things out Clarification Decision making			Decision Making
		Social skills	Advice Informed Choice			Advice
	Individual concerns		Guiding Guidance			Guidance

Initial Themes		Primary Themes		Secondary Themes		
Pre Existent	Graphics (PCP'S)	Interviews	Interviews & Video	Conceptual	Main Theme	Sub Theme
	Community Knowledge		Connections Checking things out Assessment			Community knowledge
	Resource deficits		Resources			Resource Knowledge
		Labelling Behaviour	Problem solving			Problem solving
			Right people			Others
			Positive values Positive support			Shared Values
			Negative values Negative support Negative treatment Group dynamics Labelling Lack of autonomy Lack of power Ownership Vulnerability Environment			

Footnote.

Themes are developed and move down the table in each section for example, under Initial themes there were 5 pre-existent themes. PCP, Choice, Control, Social inclusion and Hopes/Dreams. Following across the rows it can be seen that PCP was later removed as a conceptual theme(as a result of secondary thematic analysis).

This resulted in Choice being represented as the only conceptual theme in the Secondary theme column. Choice was represented consistently across all the data .This is indicated when viewed across the data and thematic development from Initial, Primary and Secondary thematic columns. The colour coding indicates that a conceptual, main theme, or sub theme developed from the data.